Brainwave-The Irish Epilepsy Association T/A Epilepsy Ireland

Reports and Financial Statements for the financial year ended 31 December 2021

REPORTS AND FINANCIAL STATEMENTS FOR THE FINANCIAL YEAR ENDED 31 DECEMBER 2021

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DIRECTORS AND OTHER INFORMATION

| DIRECTORS | Ms C. Grieve (Chairperson) Ms. H. Behan Mr M. Dowdall Mr P. Fahey Ms M. Fitzsimons Mr D. Gray Mr A. Kealy Ms A. Kilroy Prof. M. King Mr P. Kehoe Mr S. O'Brien Ms C. O'Dea |
|---------------------------------|---|
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| CHARITY NUMBER | CRA (Charities Regulator): 20010553 CHY (Revenue): 6170 |

DIRECTORS' REPORT

The directors present their annual report and the audited financial statements of the company for the financial year ended 31 December 2021.

OBJECTIVES AND ACTIVITIES

Brainwave the Irish Epilepsy Association, trading as Epilepsy Ireland is the national organisation committed to working for, and to meeting the needs of everyone with epilepsy in Ireland and their families and carers. Set up in 1966, the charity's vision is to achieve a society where no person's life is limited by epilepsy.

Epilepsy affects approximately 40,000 people in Ireland, and there are an estimated 1,300–2,100 new diagnoses each year. Characterised by recurring seizures, it affects people of all ages, including an estimated 10,000 – 15,000 children under the age of 16.

Up to 15,000 people are living with uncontrolled seizures and for this group in particular, epilepsy can be a source of long-lasting and significant, yet often hidden disability. The condition can affect all aspects of a person's life including education, employment, psychological & social functioning, self-esteem, and independent living. People with epilepsy must also cope with the physical impact of seizures, the side-effects of medications and for many, the social stigma and economic impact that can be associated with it. There is also an increased risk of mortality associated with epilepsy with an estimated 130 epilepsy-related deaths in Ireland each year.

Epilepsy Ireland's work is centred on reducing the burden of the condition for those living with epilepsy and their families. It does this by focusing on six overarching organisational aims as identified in the 2017-2021 Strategic Plan:

- Strategic Aim 1: To provide quality and relevant support, information & advice, meeting the needs of people with epilepsy, their families and carers, professionals and the wider community.
- Strategic Aim 2: To communicate effectively with stakeholders; to raise awareness and to improve public understanding of epilepsy; and to advocate for the rights of those with epilepsy, their families and carers.
- Strategic Aim 3: To provide relevant training and education services to people with epilepsy, their families, and healthcare and other professionals.
- Strategic Aim 4: To undertake, encourage, fund and communicate research into the causes of, cures for, and management of epilepsy and the psychosocial effects of the condition.
- Strategic Aim 5: To support people with epilepsy by raising the funds necessary to ensure the short-term funding requirements and long-term sustainability of the organisation.
- Strategic Aim 6: To operate a stable progressive organisation meeting all regulatory requirements and striving to implement best-practice standards in the areas of governance, organisational quality, human resources and financial management.

DIRECTORS' REPORT (CONTINUED)

2021 was the fifth and final year of the current Strategic Plan. Implementation of the ambitious objectives set by the Board in 2017 have been hindered by the COVID-19 pandemic since early 2020, which has had a significant effect on the organisation's community-based services and training, as well as its ability to raise the funds needed to sustain and develop its work.

However, as detailed throughout this Director's Report, the organisation has remained financially resilient while ensuring that services and programmes were adapted to support our service users in the new environment. Our Report will detail the activities, challenges and achievements for 2021 under each of the organisation's six strategic aims.

ACHIEVEMENTS AND PERFORMANCE

Strategic Aim 1: To provide quality and relevant support, information & advice, meeting the needs of people with epilepsy, their families and carers, professionals and the wider community.

At the core of Epilepsy Ireland's mission are the support and education services we provide for people with epilepsy and their families. These include one-to-one support, community and hospital-based outreach services; educational programmes, support groups, events & seminars, a range of resources and publications, personal advocacy and individual & group-based self-management programmes.

Our support services are provided by a team of 11 Community Resource Officers (CROs) based in Dublin, Cork, Galway, Shannon, Kilkenny, Killarney, Tullamore, Letterkenny/Sligo and Dundalk. In addition, services are provided by the National Information Officer and through the Epilepsy Ireland-funded Advanced Nurse Practitioner post at Beaumont Hospital.

Our services aim to support people with epilepsy and their families at all stages of their epilepsy journey and 2021 was an extremely busy year for our frontline services despite the challenges posed by the ongoing COVID-19 pandemic. Remote working continued throughout the year and public health advice meant that opportunities for in-person events, support groups and activities were restricted. However, adaptations introduced in 2020 ensured that the services team continued to provide one-to-one and group-based services in online settings.

Increased public familiarity with technologies such as MS Teams and Zoom meant that there was a marked increase in the number of contacts with our service throughout 2021, with numbers returning to pre-Covid levels. This highlights the value of our services to the community we work with and the importance of continued accessibility during the pandemic.

Our services team continued to support public health efforts throughout the year and provide specific information concerning COVID-19 and epilepsy to the people we support. Like 2020, concerns related to the impact of COVID-19 were common, including access to medical services, social isolation (and its physical & mental health implications), risks associated with quarantining and parental queries relating to education.

DIRECTORS' REPORT (CONTINUED)

The launch of the national vaccination program also meant that our service users had numerous initial information needs about specific issues relating to their epilepsy. Our website and social media channels continued to be a particularly important source of information on COVID-related concerns and a video on vaccination was one of the most accessed pages on our website throughout the year.

A total of 22,048 contacts with our service were recorded (2020: 17,384). 11,601 of these were one-to-one contacts (2020: 11,392) by phone, email, Teams/Zoom etc. while 10,477 people attended group-based events and services across the year (2020: 5,992). Group events included educational/ awareness sessions, workshops, our national conference, and self-management & training programmes. While we look forward to returning to more in-person events in 2022, we foresee that online support will continue to be an important aspect of our service due to its popularity and greater accessibility to a wider range of service users.

The move to online delivery of services during the pandemic allowed us to provide special themed events of interest to people with epilepsy and their families throughout 2021. Using our strong relationship with the medical community and the local connections that have been established through our presence in communities across Ireland, we delivered 95 online events in 2021 featuring subject matter experts. These included events for those who were newly diagnosed; women with epilepsy; siblings of children with epilepsy; and parents of children with epilepsy. Other themes included events focused on diet; mental health; medical cannabis in the treatment of epilepsy; and the Ketogenic diet amongst many more. In total, 2,745 people attended these events during 2021.

Epilepsy Ireland's support groups provide a safe environment for people with epilepsy and their families to discuss living with the condition in a peer environment. In 2021, 52 online groups were facilitated (2020: 61); with parent-specific groups supported in some regions. In total there were 294 attendees throughout the year (2020: 220).

The Living Well with Epilepsy programme is a core element of our service especially for new service users and those with a new diagnosis. Delivered by our CRO team, the main aim of the service is to help people with epilepsy or parents of children with epilepsy to understand the condition and to provide them with the tools needed to better understand and self-manage epilepsy. In 2021, the programme material was fully updated and redesigned. 234 individuals attended the Living Well with Epilepsy programme in both individual and group settings (2020: 313).

Our STEPS self-management programme for people with epilepsy covers all aspects of epilepsy management and provides broader support and understanding of emotional and mental health, management of stress and positive thinking. In 2021, there were 23 sessions held.

After a gap in 2020, our National Conference returned for 2021 in online form. The conference consisted of seven sessions across three days including sessions for teens on managing their epilepsy; a session on seizure detection devices & alarms; a roundtable discussion on the use of medical cannabis in epilepsy; and an epilepsy research themed session on recent developments. The flexibility provided by the online format ensured a higher attendance than in-person events, with almost 400 people attending over the three days.

DIRECTORS' REPORT (CONTINUED)

As part of Brain Awareness Week 2021, El joined with Migraine Ireland, Acquired Brain Injury Ireland, and MS Ireland to organise a series of seven public events entitled "Building Brain Health while living with a neurological condition". The events featured leading experts in the fields of mental health, physical therapy and psychology and over 900 people attended the virtual events across the week, highlighting the added value or collaboration and partnership between the wider neurological community in supporting our service users.

Work on the Slaintecare Integration Fund project to develop and deliver an education programme for people with a new diagnosis of epilepsy in conjunction with the HSE's epilepsy service was completed. While the initial plan to deliver the project through in-person groups had to be reconsidered due to COVID-19 in early 2020, a re-scoping meant that virtual education sessions continued through 2021. These included large format sessions led by consultant neurologists, while more frequent smaller workshops were facilitated by EI CROs and HSE epilepsy specialist nurses. CROs also provided individual follow up with each attendee as part of the programme.

We continued to fund a Registered Advanced Nurse Practitioner (RANP) post at Beaumont hospital, which has a focus on services for women with epilepsy. The RANP provides outreach clinics in Beaumont Hospital, the National Maternity Hospital, the Rotunda and Our Lady of Lourdes hospital in Drogheda. During 2021 a satellite clinic at St James's/ Coombe was also added. The RANP also provides specialised epilepsy advice and support to Epilepsy Ireland CROs and National Information Officer, participates in Epilepsy Ireland workshops, talks and seminars and contributes to our information materials. In 2021, the RANP recorded 1,473 contacts (2020: 761).

Strategic Aim 2: To communicate effectively with stakeholders; to raise awareness and to improve public understanding of epilepsy; and to advocate for the rights of those with epilepsy, their families and carers.

International Epilepsy Day

Our flagship public awareness campaign centres around International Epilepsy Day in February each year. The theme for 2021 was "Time. Safe. Stay!", three simple words that summarise the key actions to take when responding to a person experiencing a seizure.

#EpilepsyDay is fronted by Epilepsy Ireland volunteers and in 2021, the leading lights were Nicola O'Sullivan, Grace D'Arcy, Leah Murphy, Wayne O'Reilly and Oliver Kilmartin. The pandemic presented a great challenge to developing creative content, but this was overcome by our volunteers recording videos from home which were then worked into videos for social and online distribution. Videos used the analogy of a computer crashing and glitching to explain in plain English what is happening in the brain before, during and after a seizure.

Digital advertising was placed on leading websites such as RTÉ and the Irish Times, while print advertising appeared in the Irish Times and across regional media. Volunteers took to the airwaves to speak about epilepsy, our campaign and Time, Safe, Stay. There was also significant social media reach with posts on Facebook reaching over 200,000 people while #EpilepsyDay trended on Twitter across the day. Several politicians supported the campaign, including the Minister for Health who recorded a special message to mark #EpilepsyDay. Long-time supporter of Epilepsy Ireland, former Ireland rugby head coach Joe Schmidt also appeared on the Late Late Show to promote the message of Time, Safe, Stay.

DIRECTORS' REPORT (CONTINUED)

The campaign was positively received by the public and our service users for its clear analogy and simple first aid message. It was later shortlisted for an ICAD advertising award, while the previous 2020 campaign was shortlisted for the Inaugural Effie's award. Though unsuccessful on both occasions, it is positive and encouraging to see our campaigns are being recognised for their impact in changing public perceptions and improving knowledge of epilepsy.

National Epilepsy Week

For National Epilepsy Week in May, we highlighted one key issue each day which is impacting on the lives of people with epilepsy and their families. These included: Sodium Valproate; access to free travel; reasonable accommodations during state exams; Online Media & Safety Regulation Bill and the Medical Cannabis Access Programme. In advance of the week, we highlighted these key issues with TDs and Senators. During the Week, we used our social channels to provide the public with an oversight of each issue and asked our supporters to contact their representatives to raise the issues directly. The campaign helped to advance these issues considerably, in particular the issue of online safety for people with photosensitive epilepsy.

A particular highlight of the week was Senator Denis O'Donovan publicly speaking about his epilepsy diagnosis in the Senate chamber. This received national headlines and it was an important development for the epilepsy community to see an elected representative speaking about their personal journey with the condition.

SUDEP Action Day

SUDEP Action Day provides a much-needed annual platform to raise awareness of Sudden Unexpected Death in Epilepsy (SUDEP) both publicly and in the epilepsy community. The day also presents an opportunity to remember those who have sadly passed away due to SUDEP. In 2021, we shared two powerful testimonies from families who had lost a loved one due to SUDEP with Arabella Scanlon writing about the loss of her daughter Brianna and journalist Bill Linnane, writing about the loss of his sister Lucy.

We also highlighted the Epilepsy Deaths Register a research collaboration between Epilepsy Ireland and SUDEP Action in the UK. This register allows bereaved families, health professionals and others to provide details of the death of a person with epilepsy. The Register aims to collect and analyse data to better understand the causes and circumstances that surround epilepsy deaths. The Register website was updated fully in 2021 and Epilepsy Ireland contacted all coroners nationwide to encourage them to provide data to the register.

Infantile Spasms Awareness Week

A new development in 2021 saw Epilepsy Ireland joining the Infantile Spasms Awareness Network. This is an international group of organisations dedicated to raising awareness of Infantile Spams, a type of seizure that occur in infants which can be extremely subtle and if undetected, can have a serious impact on a child's development. During the week, we worked with Our Lady's Children's Hospital, Crumlin to spread awareness of IS amongst new parents and established a new resource on our website including a video with paediatric neurologist, Dr Mary O'Regan. We look forward to building on this promising start in 2022.

DIRECTORS' REPORT (CONTINUED)

Epilepsy Advocacy

One of our key strategic aims at Epilepsy Ireland is advocating for the needs of people with epilepsy and to reflect the increasing strategic importance of advocacy, the role or Communications Officer was expanded in 2021 to that of Advocacy & Communications Manager. Progress was made in 2021 on several campaigns as outlined below.

Sodium Valproate

We continued to work with our colleagues in OACS Ireland regarding the establishment of an inquiry into the historical licensing and prescribing of Sodium Valproate (Epilim) in Ireland. The HSE estimates that up to 1,250 children have been impacted by the teratogenic effects of the drug since the 1970s and because of this, the Minister of Health announced in November 2020 that an inquiry would be established. Although little progress was made in getting the inquiry established in the first half of the year, productive discussions began with the Department of Health in the latter part of the year regarding the proposed Terms of Reference for the inquiry. We expect that the inquiry will be formally established in 2022.

Alongside the inquiry, we continued to campaign for an improved, coordinated national approach to risk management in pregnancy through the establishment of a Valproate Stakeholder Group, and for the appointment of additional epilepsy nurse specialists to improve HSE capacity to appropriately manage risk communication and management.

Reasonable Accommodations during State Exams

Significant progress was made on this long-standing issue in 2021 when the Minister for Education announced her intention to provide an alternate sitting of Leaving Cert Examinations in 2022 for students who are *"unable to sit the main set of examinations due to ... categories of serious illness to be determined."* Due to the unpredictable nature of epilepsy and the tendency for seizures to occur at times of high stress, Epilepsy Ireland has campaigned for alternate sittings and other accommodations such as increased continuous assessment and split exams for several years. We welcomed this announcement and although the detail of plans had not been finalised by year end, we continued to work with legislators and the Department to ensure that students with epilepsy are accommodated within the new provisions.

Free Travel & Epilepsy

Epilepsy Ireland has campaigned for many years for access to the Free Travel Scheme for people with epilepsy who are unable to drive due to their epilepsy diagnosis. At present, this is not an automatic entitlement and throughout 2021, we mobilised strong support from elected representatives nationally and encouraged our members to do likewise. We also submitted a pre-budget submission on this issue to the Ministers for Finance, Public Expenditure and Reform, and Social Protection. Towards the end of 2021, the Minister for Social Protection confirmed for the first time that she would meet with Epilepsy Ireland to discuss our proposals in detail. We look forward to pursuing this issue in 2022.

DIRECTORS' REPORT (CONTINUED)

Oireachtas Committee on Media

Epilepsy Ireland appeared before the Oireachtas Committee on Media in 2021 as part of their pre-legislative scrutiny of the proposed Online Safety & Media regulation Bill. We highlighted the need for the legislation to protect people with photosensitive epilepsy in Ireland from targeted online attacks using flashing images to deliberately provoke seizures. This has unfortunately become an issue in other jurisdictions and in our presentation, we acknowledged how it was unclear if existing laws were sufficient to deal with such instances.

As a result of our advocacy, we received confirmation from the Attorney General that such attacks could and would be prosecuted under existing criminal law, specifically as assault. This is a welcome clarification that will protect people with photosensitive epilepsy from such attacks becoming commonplace.

Epidyolex Reimbursement

In late 2021, the HSE confirmed that CBD-based medication Epidyolex would be reimbursed in Ireland for use in the treatment of Dravet Syndrome & Lennox-Gastaut Syndrome where certain criteria are met. Epilepsy Ireland had campaigned for the reimbursement of this medication, including via a submission to the National Centre for Pharmacoeconomics in 2020. The approval means that the drug will be available under the medical card, Long-term Illness and Drugs Payment Schemes from 2022.

Other advocacy

Throughout 2021, we continued our work with umbrella organisations both nationally and internationally including the Neurological Alliance of Ireland (NAI); Disability Federation of Ireland (DFI); Health Research Charities Ireland (HRCI); International Bureau for Epilepsy (IBE) and the International League Against Epilepsy (ILAE). The NAI's Patients Deserve Better campaign was a particularly successful collaborative advocacy campaign, working to address the shortfall of specialist neurology posts in Ireland. We also continued to work with the medical profession on issues including advancing epilepsy e-health and on improving access to the medical cannabis access programme (MCAP) for people with epilepsy.

Strategic Aim 3: To provide relevant training and education services to people with epilepsy, their families, and healthcare and other professionals.

Training in Epilepsy Awareness & the Administration of Buccal Midazolam

Since 2009, Epilepsy Ireland has been providing a training programme in Epilepsy Awareness & the Administration of Buccal Midazolam (BM) to health and allied health professionals, including teachers and SNAs. Buccal Midazolam is a rescue medication which is administered during a seizure to reduce seizure duration. The medication can prevent hospital admissions and reduce the incidence of potentially dangerous prolonged seizures. The aim of the training programme is for participants to develop a greater understanding of epilepsy, understand the role of the emergency rescue medication and receive instruction in the correct administration of BM. The training is delivered by Epilepsy Ireland's Training Manager and Community Resource Officers.

DIRECTORS' REPORT (CONTINUED)

The programme was adapted for online delivery in response to COVID-19 during 2020 and online delivery continued in 2021, with a small number of in-person sessions held in accordance with public health guidelines. In 2021, demand returned to pre-pandemic levels with 3,341 healthcare professionals and teachers trained over 271 courses, a significant increase from the 2,057 trainees and 163 courses in 2020.

Buccal Midazolam Training for Parents/Carers

We also provide demonstrations for parents and carers in administering BM. In 2021, 55 individual online information and demonstration sessions on Buccal Midazolam were delivered, with 194 parents/ caregivers attending (2020: 43;144).

Training for Success

There was a welcome return to the classroom for our students participating in the 2021/22 Training for Success (TFS) programme. TFS is a QQI Level 5 course which is run by Epilepsy Ireland in IT Sligo (now Atlantic Technological University Ireland, Sligo) and is funded by Mayo Sligo Leitrim Educational Training Board. The one-year course is for people with epilepsy who may experience difficulty in entering the workforce or pursuing further education due to the impact of their epilepsy. Operating since 1998, TFS is one of the most unique pillars of our service and one which has a proven impact, with 85% of those who complete the course going on to further education or employment. Modules include Epilepsy Management, Research and Study Skills, Word Processing, Communications, Teamwork, Health and Safety at Work, Internet, Customer service & Work Experience.

Having been delivered entirely online in 2020, students were back on campus in 2021 and eight students began the 2021/22 term in September. 11 students had begun the previous 2020/21 programme with six completing in August. Four of the graduates went on to further/ 3rd level education with two progressing to employment.

Epilepsy Awareness in the community

While the frontline of our service is supporting people with epilepsy and their families, as a community-based organisation, our work also extends to the wider community and there has been a particular demand in recent years from schools, preschools, and other education settings for epilepsy awareness training. Our programme aims to raise awareness of epilepsy for those with the responsibility for ensuring a safe education environment. The content can be tailored but typically includes an introduction to epilepsy; a brief classification of seizure activity; and most importantly, steps that should be taken in responding to seizures at school. In 2021, we delivered 160 talks to education providers, with over 3,100 attendees (2020: 129; 2,463). Specific events were also organised in 2021 for general practitioners, nurses and employers during the year.

Strategic Aim 4: To undertake, encourage, fund and communicate research into the causes of, cures for, and management of epilepsy and the psychosocial effects of the condition.

Since 2009, Epilepsy Ireland has operated a Research Funding Scheme, investing in high quality, high-impact Irish epilepsy research. Studies funded have included basic, clinical, psychosocial, genetic and health services research. The scheme aims to support research that has the potential to add significantly to existing knowledge into the causes, cures, care, treatment, impact and effect of any type of epilepsy, including SUDEP. Prior to 2021, over €1.1 million had been invested in 15 projects and in 2021, one new project was funded.

DIRECTORS' REPORT (CONTINUED)

New & Ongoing projects funded

The new study takes place at NUI Galway and is led by James Britton under the supervision of Dr Leo Quinlan (Department of Physiology, School of Medicine). It will investigate an emerging technology called ultrasonic stimulation as a potential non-invasive novel intervention in a group of rare, difficult to treat epilepsies such as Dravet Syndrome & Lennox-Gastaut Syndrome. The work will study whether this technology can regulate electrical activity in the brain associated with seizures, and if successful, may lead to the development of new treatments in the future. Our investment totals €30,656 over two years via the Irish Research Council's Enterprise Partnership Scheme.

Work continued in 2021 on several other projects previously supported by Epilepsy Ireland. Unfortunately, COVID-19 has had an impact on the completion of ongoing medical research and some projects have been delayed and provided with extensions. Ongoing projects include:

- An Analysis of the Current Implementation and Societal Impact of Group 1 and Group 2 Driving Restrictions in both Newly Diagnosed and Established Patients with Epilepsy (RCSI, 2020; €15,000)
- Epilepsy Mortality in Ireland (HRB, 2020: €25,000)
- The microbiome as an environmental trigger for autoimmune epilepsy (RCSI, 2018: €74,500)
- MicroRNAs in the mechanism of ketogenic diet therapies and as biomarkers in paediatric epilepsy (RCSI, 2016: €72,000)

Outcomes of research projects funded

Since 2016, Epilepsy Ireland has supported research at Queens University Belfast investigating whether untrained pet dogs could predict seizures by recognising and reacting to particular odours associated with seizures in humans. In 2021, findings were published by Dr Neil Powell highlighting that all dogs in the study displayed behavioural changes when confronted with seizure-related odours compared to non-seizure control odours. The study received significant media attention and has important practical implications for people with epilepsy – it is hoped that by training dogs to alert their owners of an impending seizure, we can reduce the unpredictable nature of the condition, the injuries associated with seizure-related falls and improve people's quality of life and physical & psychological well-being. This work will also support Epilepsy Ireland's advocacy objectives in 2022 and beyond.

Epilepsy Ireland also previously supported research on the development and role of an epilepsy electronic patient portal (e-Portal) as part of the HSE's Epilepsy Electronic Patient Record (EPR). On completion of the study, findings were published in two papers in the journal *Epilepsy & Behaviour* in 2021. The importance of e-health innovations like the e-portal was brought to the fore during Covid-19 and the work was highlighted as an example of good e-health practice at the Opening Symposium of the 2021 International Epilepsy Congress. Epilepsy Ireland and medical professional colleagues will continue to work on embedding the e-Portal in the ongoing development of the Epilepsy EPR.

DIRECTORS' REPORT (CONTINUED)

Research Communications

Communicating research to patients and the public is also a priority for Epilepsy Ireland and in 2021, we partnered with RCSI/ FutureNeuro on a series of SFI-funded online workshops which brought together researchers, healthcare professionals, people with epilepsy and their families in one forum to discuss key epilepsy research areas. The areas of focus were set in consultation with Epilepsy Ireland service users and were SUDEP, temporal lobe epilepsy, gene therapy and the use of technology in monitoring epilepsy. Each workshop featured a presentation from a leading expert or researcher working on these topics followed by group discussion on the importance of research; how it can be better communicated; and how the research community can help foster in an environment that includes people with epilepsy within their projects. The events also addressed important considerations about finding reliable research online and empowering people to better understand and interpret scientific publications.

Epilepsy Ireland continually works to promote research volunteering and support researchers and students in non-financial ways. One of the ways we do this is to connect people with epilepsy to the research community through our website and other communication channels. Throughout the year, we shared several volunteering opportunities on projects investigating subjects such as the impact of sleep-deprived EEGS; outcomes from childhood epilepsy; the impact of COVID-19; and the disclosure of epilepsy.

Future Research plans

In September 2021, Epilepsy Ireland announced the 8th Research Call since our research funding scheme was established in 2010. Applications were requested for 1–3-year projects to a maximum of €50,000 p.a. Following a consultation with EI service users, the following priorities were set for the call: SUDEP & Epilepsy Mortality; Cannabinoids in Epilepsy; Epilepsy in Women; Psychosocial aspects of epilepsy; and Genetic and molecular mechanisms of epilepsy. A total of six proposals were received and at year end, international peer-review of applications was set to begin. At the end of the assessment stage, the highest-ranking proposals will be submitted to the Health Research Board in 2022 for co-funding under the HRB-HRCI Joint Funding Scheme. Successful projects will be co-funded by Epilepsy Ireland and the HRB from Autumn 2022.

In addition, Epilepsy Ireland partnered on three applications to the Irish Research Council's Enterprise Partnership Scheme in December 2021. Under this scheme, EI would fund 1/3 of the research costs on successful applications. Outcomes of these applications will be known in the second quarter of 2022.

Other developments

Epilepsy Ireland partnered with FutureNeuro and the Insight Centre for Data Analytics on a successful EU funding application to establish NeuroInsight, a post-doc research programme that will fund 33 fellowships in Ireland from 2022. The programme will fund data science projects on AI, machine and deep learning, data analysis and integration that address challenges arising from epilepsy and other neurological conditions.

Epilepsy Ireland CEO Peter Murphy co-authored two papers in the leading journal *Epilepsia* on the impact of the COVID-19 pandemic on both epilepsy research and epilepsy care. Over 70 EI service users participated in the epilepsy care study which gathered almost 600 respondents from around the world.

DIRECTORS' REPORT (CONTINUED)

Epilepsy Ireland are local partners with two leading research institutions – Dublin City University and RCSI – on the National PPI Ignite network. The network aims to change research culture to better involve patients and the public in research decision-making processes and in the research process itself.

Strategic Aim 5: To support people with epilepsy by raising the funds necessary to ensure the short-term funding requirements and long-term sustainability of the organisation.

Epilepsy Ireland's main source of funding is through seven Service Level Agreements (SLAs) with HSE Community Healthcare Organisations (CHOs) across the country. These Section 39 agreements support staffing and costs relating to many of our support and education services.

A series of historical funding cuts to Section 39 funding incurred in the early 2010s combined with increasing costs, inflation and rising demand for our services in recent years has meant that HSE funding does not cover the full cost of the funded services.

In 2021, there was a funding shortfall of €34,592 (2020: €68,918), which has been met by utilising unrestricted reserves. The shortfall has been reduced in recent years through a combination of cost control measures; the adaptation of remote working and by sourcing new grant income through the Scheme to Support National Organisations (SSNO) and the Slaintecare Integration Fund. Total grant income in 2021 (including HSE, SSNO, Slaintecare etc.) was €826,193 (2020: €1,161,238). We remain hopeful that the HSE's Dialogue Forum with Voluntary Organisations will work to address long-standing funding and other concerns relevant to Section 39 organisations like Epilepsy Ireland.

Total non-grant income in 2021 was €706,187 (2020: €799,885). This includes income from fundraising activities, philanthropic grants, corporate support, training income, interest received and miscellaneous income. It also includes an in-kind donation of services worth €7,563 for International Epilepsy Day 2021 which is recorded in accordance with Charities SORP.

Fundraising in particular has been particularly hit by the pandemic and is approx. 50% lower than in prepandemic years. Community fundraising activities, critical to Epilepsy Ireland, like church gate collections, Rose Week and many supporter events/challenges were all either cancelled or moved online in 2021, as was also the case in 2020. However, some activities continued with relatively little disruption including the Time for a Break monthly draw; the members' raffle; online fundraising and donations. We are also encouraged by the possibilities offered by Purple Day[®], the international grassroots epilepsy day held in March each year. In 2021, we launched an interactive online map on which the public could donate and place a pin where they donated from – in an effort to 'turn Ireland purple'. This initiative alongside other digital events and challenges saw income increase slightly for Purple Day[®] in 2021.

The board and management recognises that Epilepsy Ireland's traditional community-based model of fundraising needs to evolve in order to sustain the charity's funding needs into the future. This will involve enhancing our digital fundraising model and exploring new opportunities in corporate fundraising, regular giving, and other potential channels. Another goal is to improve our use and analysis of data in support of fundraising efforts. These and other ambitious targets will be a central component in our new strategic plan 2022-2026.

DIRECTORS' REPORT (CONTINUED)

We are very grateful to all our donors and supporters who supported Epilepsy Ireland in what was a very difficult and uncertain year for everyone financially. A particular highlight was the appearance of former Irish Rugby Head Coach on the Late Late Show in January 2021, whose appearance helped to raise over €20,000 for Epilepsy Ireland.

The phenomenal fundraising carried out during the year by the family and friends of Epilepsy Ireland volunteer, Louise Young who died in January from Sudden Unexpected Death in Epilepsy (SUDEP) deserves particular mention. Despite their tragic loss, over €36,000 was raised in Louise's memory and these funds have been restricted, with the agreement of Louise's family, towards the launch of a new, much-needed service in 2022. We are also grateful for the support of Louise's employer, Procurement Leaders for supporting the fundraising efforts.

Our training programme in epilepsy awareness and the administration of Buccal Midazolam continued online throughout the year and income earned through this service was €151,050 (2020: €92,904). Income from this service returned to pre-pandemic expectations with training mainly continuing to be delivered online.

Strategic Aim 6: To operate a stable progressive organisation meeting all regulatory requirements and striving to implement best-practice standards in the areas of governance, organisational quality, human resources and financial management.

Structure, Governance & Management

The Epilepsy Ireland board of directors is responsible for setting the direction and strategy of the charity and for ensuring that it is effectively and responsibly governed. The Board delegates operational leadership, management and strategic implementation to the chief executive who oversees the wider management and staff team and reports to the Board regularly on all services and activities, as well as administrative and financial matters.

The board has established the following sub-committees which considers and makes recommendations to the board on matters specified in their terms of reference: Finance & Audit sub-committee; Governance & Nominations sub-committee; Quality & Safety sub-committee; Remuneration sub-committee; Business Development & Sustainability sub-committee.

The board is comprised of 13 volunteer members (as of 31 December 2021), drawn from a variety of backgrounds, skillsets and experiences. 10 board members have a direct personal connection to epilepsy (i.e., either they or a close family member lives with the condition).

The board is committed to the highest standards of corporate governance and understand that this is a key obligation, not only in ensuring best practice in fulfilling the organisation's mission, but also in maintaining the trust and confidence of members, service users, volunteers and donors.

The board governs the organisation in accordance with its constitution, which specifies that board members may ordinarily serve up to two four-year terms. Four board members stepped down in 2021 (C Saarsteiner, J Senior, T Dagge & T Caravousanos) and four new board members were elected to the board (M King, H Behan, A Kilroy and S O'Brien). The incoming board members bring particular skills and experiences that help meet the needs and gaps identified in the board's annually updated development plan.

DIRECTORS' REPORT (CONTINUED)

The board operates in accordance with a range of governance policies and procedures and with reference to strategic and operational plans. The chief executive provides detailed updates of progress against the operational plan and budget at each board meeting.

Seven board meetings were held in 2021 (2020: Nine). All meetings were held remotely. During the year, the board:

- Closely monitored the organisations response to the challenges presented by COVID-19 especially in the areas of service provision and the management of income and expenditure.
- Approved an annual plan and budget for the year and monitored progress against these throughout the year.
- Reviewed and approved actions on the organisation's risks and risk management strategies.
- Agreed to undertake a new strategic planning process for 2022-2026; established a strategic planning group and began work on the development of the plan, including stakeholder consultations.
- Completed all work ahead of obtaining the IQ quality standard
- Approved the organisation's full compliance with the Charities Regulator Governance Code.
- Approved the reorganisation of the charity's deposits.
- Completed a board performance review.
- Approved a new Employee handbook and developed a schedule for the review of all internal policies and procedures
- Agreed to launch a new round of the Epilepsy Ireland Research Funding Scheme
- Received detailed departmental updates from management team/ staff members at each of its meetings.

The organisation maintains the Charities Institute Ireland 'Triple Lock' standard of compliance with the Guidelines for Charitable Organisations on Fundraising from the Public; the Governance Code for the Community and Voluntary Sector; and preparing our financial statements in accordance with SORP for charities. Epilepsy Ireland has also attained the Improving Quality Foundation quality mark. IQ is a standard developed specifically for small non-profit organisations, assessing the organisations governance and management under the indicators of accountability, welcoming, effectiveness and sustainability. Epilepsy Ireland previously held the Trusted Charity standard from 2015–2021.

Risks and uncertainties

The Board has approved a risk management policy for the organisation and maintains a risk register detailing all organisational risks, the mitigation measures in place and actions needed to minimise these risks. The register is reviewed regularly the Board and by the Finance & Audit and Quality & Safety sub-committees. Risks are analysed under human resources, information technology, fundraising, finance, services, governance, strategic and other. Risks are rated on an inherent and residual basis as high, medium or low risks based on the likelihood of occurrence and potential impact.

In 2021, the COVID-19 pandemic and its impact continued to influence the organisation's risk profile and management. From 2020, the Board agreed to review the register twice a year and close monitoring is undertaken.

DIRECTORS' REPORT (CONTINUED)

Financial risks continue to be the highest priority. The Board acknowledges the organisation's dependence on HSE Section 39 funding to continue providing core services. The pandemic has also resulted in fundraising income being severely depleted since 2020 and this was mitigated by accessing funding through the COVID-19 Stability Fund in 2020. Other mitigation measures include the close monitoring of expenditure and forecasts by the Finance & Audit sub-committee and Board, and by taking a conservative approach to planned expenditure.

The lifting of restrictions in early 2022 means that most of the organisation's community-based fundraising will re-commence during the year and it is anticipated that fundraising performance will improve from 2020 and 2021 levels. However, the board acknowledges that this is dependent on the external environment and public health measures as well as the potential impact of the prevailing economic environment.

The Board is confident that assumptions made in budgeting and planning for 2022 are appropriate and that it can take any further steps required including additional measures to reduce costs or utilising unrestricted reserves if required.

An assessment of strengths, weakness, opportunities, and threats was an integral part of the 2021-22 strategic planning process. The resultant strategic plan commits the organisation to delivering on its vision and mission to meet the needs of people with epilepsy and their families, while remaining cognizant of financial risks and uncertainties.

Internal controls

The board has established procedures of compliance which addressed the board's wider responsibilities – to maintain, review and report on internal controls, especially all financial operations. The board has regularly reviewed policies and procedures in relation to the receipt, recording and control of all income received. The most recent review was in 2021.

The Finance and Audit sub-committee reports directly to the board through the Treasurer and Chair on all aspects of controls and risks. A detailed budget is prepared, reviewed and approved annually by the board. The budgeted income and expenditure is monitored to ensure alignment with plans and with financial resources available and forecasts are updated ahead of each sub-committee and board meeting.

| RESULTS FOR THE FINANCIAL YEAR | 2021 € | 2020 € |
|---|-----------|-----------|
| Net (expenditure)/income for the financial year | (25,198) | 138,771 |

DIRECTORS' REPORT (CONTINUED)

GOING CONCERN

The Covid-19 pandemic has continued to negatively affected the organisation's operations and incomegenerating capacity, as described within the Risks and Uncertainties section. The Board recognises the organisation's ongoing dependence on HSE and other state funding and supports to deliver its core services. To date, these funding agreements have been maintained at pre-pandemic levels.

Based on the easing of public health restrictions in 2022; our current forecasts and projections; and the reserves held by the company; the Board has a reasonable expectation that there are adequate resources to operate within its current cash flows and reserves for the foreseeable future.

Therefore, the Board continues to adopt the going concern basis of accounting in preparing the annual financial statements. Accordingly, these financial statements do not include any adjustments to the carrying amount and classification of assets and liabilities that may arise if the company was unable to continue as a going concern. Further details can be found in note 2 to the financial statements.

DIRECTORS AND SECRETARY

A list of current directors is shown on page 2. The directors, and secretary, who served at any time during the financial year except as noted, were as follows:

Directors:

Ms C. Grieve (Chairperson) Ms H Behan (appointed 5th July 2021) Mr T. Caravousanos (resigned 30th September 2021) Mrs T. Dagge (resigned 30th September 2021) Mr M. Dowdall Mr P. Fahey Ms M. Fitzsimons Mr D. Gray Mr A. Kealy Mr P. Kehoe Ms A. Kilroy (appointed 5th July 2021) Prof M. King (appointed 5th July 2021) Mr S. O'Brien (appointed 5th July 2021) Ms C. O'Dea Ms C. Saarsteiner (resigned 26th May 2021) Major General V. Savino (resigned 1st April 2022) Dr J. Senior (resigned 30th September 2021)

Secretary:

Ms C. O'Dea

DIRECTORS' REPORT (CONTINUED)

POST BALANCE SHEET EVENTS

There have been no significant events affecting the company since the financial year end. As described above (Risks and Uncertainties section), the Board will continue to monitor the effects of the Covid-19 pandemic and other external factors and take appropriate measures to adapt as appropriate to ensure key services and activities continue to be delivered.

ACCOUNTING RECORDS

The measures that the directors have taken to secure compliance with the requirements of sections 281 to 285 of the Companies Act 2014 with regard to the keeping of accounting records, are the employment of appropriately qualified accounting personnel and the maintenance of computerised accounting systems. The company's accounting records are maintained at the company's registered office at 249 Crumlin Road, Dublin 12.

DISCLOSURE OF INFORMATION TO AUDITORS

In the case of each of the persons who are directors at the time the directors' report and financial statements are approved:

- A) So far as the director is aware, there is no relevant audit information of which the company's auditors are unaware; and
- B) Each director has taken all steps that ought to have been taken by the director in order to make himself/herself aware of any relevant audit information and to establish that the company's auditors are aware of that information.

AUDITORS

The auditors, Deloitte Ireland LLP, Chartered Accountants and Statutory Audit Firm, continue in office in accordance with Section 383(2) of the Companies Act 2014.

Approved by the Board and signed on its behalf by:

Triede.

Cathy Grieve Director

Paul Kehoe Director

Date: 24th May 2022

DIRECTORS' RESPONSIBILITIES STATEMENT

The directors are responsible for preparing the directors' report and the financial statements in accordance with the Companies Act 2014.

Irish company law requires the directors to prepare financial statements for each financial year. Under the law, the directors have elected to prepare the financial statements in accordance with FRS 102 *The Financial Reporting Standard applicable in the UK and Republic of Ireland issued by the Financial Reporting Council* ("relevant financial reporting framework"). Under company law, the directors must not approve the financial statements unless they are satisfied that they give a true and fair view of the assets, liabilities and financial position of the company as at the financial year end date and of the profit or loss of the company for the financial year and otherwise comply with the Companies Act 2014.

In preparing those financial statements, the directors are required to:

- select suitable accounting policies for the Company Financial Statements and then apply them consistently;
- make judgements and estimates that are reasonable and prudent;
- state whether the financial statements have been prepared in accordance with the applicable accounting standards, identify those standards, and note the effect and the reasons for any material departure from those standards; and
- prepare the financial statements on the going concern basis unless it is inappropriate to presume that the company will continue in business.

The directors are responsible for ensuring that the company keeps or causes to be kept adequate accounting records which correctly explain and record the transactions of the company, enable at any time the assets, liabilities, financial position and profit or loss of the company to be determined with reasonable accuracy, enable them to ensure that the financial statements and directors' report comply with the Companies Act 2014 and enable the financial statements to be audited. They are also responsible for safeguarding the assets of the company and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities.

The directors are responsible for the maintenance and integrity of the corporate and financial information included on the company's website.

Deloitte.

Deloitte Ireland LLP Chartered Accountants & Statutory Audit Firm

INDEPENDENT AUDITOR'S REPORT TO THE MEMBERS OF BRAINWAVE – THE IRISH EPILEPSY ASSOCIATION T/A EPILEPSY IRELAND

Report on the audit of the financial statements

Opinion on the financial statements of Brainwave – The Irish Epilepsy Association T/A Epilepsy Ireland ("the company") In our opinion the financial statements:

- give a true and fair view of the assets, liabilities and financial position of the company as at 31 December 2021 and of the loss for the financial year then ended; and
- have been properly prepared in accordance with the relevant financial reporting framework and, in particular, with the requirements of the Companies Act 2014.

The financial statements we have audited comprise:

- the Statement of Financial Activities;
- the Balance Sheet;
- the Statement of Cash Flows; and
- the related notes 1 to 28, including a summary of significant accounting policies as set out in note 1.

The relevant financial reporting framework that has been applied in their preparation is the Companies Act 2014 and FRS 102 'The Financial Reporting Standard applicable in the UK and Republic of Ireland' issued by the Financial Reporting Council ("the relevant financial reporting framework").

Basis for opinion

We conducted our audit in accordance with International Standards on Auditing (Ireland) (ISAs (Ireland)) and applicable law. Our responsibilities under those standards are described below in the "Auditor's responsibilities for the audit of the financial statements" section of our report.

We are independent of the company in accordance with the ethical requirements that are relevant to our audit of the financial statements in Ireland, including the Ethical Standard issued by the Irish Auditing and Accounting Supervisory Authority, and we have fulfilled our other ethical responsibilities in accordance with these requirements. We believe that the audit evidence we have obtained is sufficient and appropriate to provide a basis for our opinion.

Conclusions relating to going concern

In auditing the financial statements, we have concluded that the directors' use of the going concern basis of accounting in the preparation of the financial statements is appropriate.

Based on the work we have performed, we have not identified any material uncertainties relating to events or conditions that, individually or collectively, may cast significant doubt on the company's ability to continue as a going concern for a period of at least twelve months from when the financial statements are authorised for issue.

Our responsibilities and the responsibilities of the directors with respect to going concern are described in the relevant sections of this report.

Other information

The other information comprises the information included in the Reports and Financial Statements, other than the financial statements and our auditor's report thereon. The directors are responsible for the other information contained within the Reports and Financial Statements. Our opinion on the financial statements does not cover the other information and, except to the extent otherwise explicitly stated in our report, we do not express any form of assurance conclusion thereon.

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INDEPENDENT AUDITOR'S REPORT TO THE MEMBERS OF BRAINWAVE – THE IRISH EPILEPSY ASSOCIATION T/A EPILEPSY IRELAND

Our responsibility is to read the other information and, in doing so, consider whether the other information is materially inconsistent with the financial statements or our knowledge obtained in the audit or otherwise appears to be materially misstated. If we identify such material inconsistencies or apparent material misstatements, we are required to determine whether there is a material misstatement in the financial statements or a material misstatement of the other information. If, based on the work we have performed, we conclude that there is a material misstatement of this other information, we are required to report that fact.

We have nothing to report in this regard.

Responsibilities of directors

As explained more fully in the Directors' Responsibilities Statement, the directors are responsible for the preparation of the financial statements and for being satisfied that they give a true and fair view and otherwise comply with the Companies Act 2014, and for such internal control as the directors determine is necessary to enable the preparation of financial statements that are free from material misstatement, whether due to fraud or error.

In preparing the financial statements, the directors are responsible for assessing the company's ability to continue as a going concern, disclosing, as applicable, matters related to going concern and using the going concern basis of accounting unless the directors either intend to liquidate the company or to cease operations, or have no realistic alternative but to do so.

Auditor's responsibilities for the audit of the financial statements

Our objectives are to obtain reasonable assurance about whether the financial statements as a whole are free from material misstatement, whether due to fraud or error, and to issue an auditor's report that includes our opinion. Reasonable assurance is a high level of assurance, but is not a guarantee that an audit conducted in accordance with ISAs (Ireland) will always detect a material misstatement when it exists. Misstatements can arise from fraud or error and are considered material if, individually or in the aggregate, they could reasonably be expected to influence the economic decisions of users taken on the basis of these financial statements.

As part of an audit in accordance with ISAs (Ireland), we exercise professional judgment and maintain professional scepticism throughout the audit. We also:

- Identify and assess the risks of material misstatement of the financial statements, whether due to fraud or error, design and perform audit procedures responsive to those risks, and obtain audit evidence that is sufficient and appropriate to provide a basis for our opinion. The risk of not detecting a material misstatement resulting from fraud is higher than for one resulting from error, as fraud may involve collusion, forgery, intentional omissions, misrepresentations, or the override of internal control.
- Obtain an understanding of internal control relevant to the audit in order to design audit procedures that are appropriate in the circumstances, but not for the purpose of expressing an opinion on the effectiveness of the company's internal control.
- Evaluate the appropriateness of accounting policies used and the reasonableness of accounting estimates and related disclosures made by the directors.
- Conclude on the appropriateness of the directors' use of the going concern basis of accounting and, based on the audit evidence obtained, whether a material uncertainty exists related to events or conditions that may cast significant doubt on the company's ability to continue as a going concern. If we conclude that a material uncertainty exists, we are required to draw attention in our auditor's report to the related disclosures in the financial statements or, if such disclosures are inadequate, to modify our opinion. Our conclusions are based on the audit evidence obtained up to the date of the auditor's report. However, future events or conditions may cause the entity (or where relevant, the group) to cease to continue as a going concern.
- Evaluate the overall presentation, structure and content of the financial statements, including the disclosures, and whether the financial statements represent the underlying transactions and events in a manner that achieves fair presentation.

We communicate with those charged with governance regarding, among other matters, the planned scope and timing of the audit and significant audit findings, including any significant deficiencies in internal control that the auditor identifies during the audit.

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INDEPENDENT AUDITOR'S REPORT TO THE MEMBERS OF BRAINWAVE – THE IRISH EPILEPSY ASSOCIATION T/A EPILEPSY IRELAND

Report on other legal and regulatory requirements

Opinion on other matters prescribed by the Companies Act 2014

Based solely on the work undertaken in the course of the audit, we report that:

- We have obtained all the information and explanations which we consider necessary for the purposes of our audit.
- In our opinion the accounting records of the company were sufficient to permit the financial statements to be readily and properly audited.
- The financial statements are in agreement with the accounting records.
- In our opinion the information given in the directors' report is consistent with the financial statements and the directors' report has been prepared in accordance with the Companies Act 2014.

Matters on which we are required to report by exception

Based on the knowledge and understanding of the company and its environment obtained in the course of the audit, we have not identified material misstatements in the directors' report.

We have nothing to report in respect of the provisions in the Companies Act 2014 which require us to report to you if, in our opinion, the disclosures of directors' remuneration and transactions specified by law are not made.

Use of our report

This report is made solely to the company's members, as a body, in accordance with Section 391 of the Companies Act 2014. Our audit work has been undertaken so that we might state to the company's members those matters we are required to state to them in an auditor's report and for no other purpose. To the fullest extent permitted by law, we do not accept or assume responsibility to anyone other than the company and the company's members as a body, for our audit work, for this report, or for the opinions we have formed.

Scothan Phelen

Siobhán Phelan For and on behalf of Deloitte Ireland LLP Chartered Accountants and Statutory Audit Firm Deloitte & Touche House, 29 Earlsfort Terrace, Dublin 2

30 May 2022

STATEMENT OF FINANCIAL ACTIVITIES (INCORPORATING INCOME AND EXPENDITURE ACCOUNT) FOR THE FINANCIAL YEAR ENDED 31 DECEMBER 2021

| | Notes | Restricted | Unrestricted | Total | Restricted | Unrestricted | Total |
|--------------------------|-------|------------|--------------|-----------|------------|--------------|-----------|
| | | Funds | Funds | Funds | Funds | Funds | Funds |
| | | 2021 | 2021 | 2021 | 2020 | 2020 | 2020 |
| | | € | € | € | € | € | € |
| INCOME FROM: | | | | | | | |
| Donations and | | | | | | | |
| Legacies | 4 | 51,766 | 224,361 | 276,127 | 252,545 | 190,628 | 443,173 |
| Charitable Activities | 5 | 826,193 | 266,365 | 1,092,558 | 1,161,238 | 218,667 | 1,379,905 |
| Other Trading | | | | | | | |
| Activities | 6 | 34,038 | 114,842 | 148,880 | 27,342 | 75,864 | 103,206 |
| Investment Income | 7 | - | 2,015 | 2,015 | - | 3,453 | 3,453 |
| Other Income | 8 | - | 12,800 | 12,800 | - | 31,386 | 31,386 |
| Total | | 911,997 | 620,383 | 1,532,380 | 1,441,125 | 519,998 | 1,961,123 |
| | | | | | | | |
| | | | | | | | |
| EXPENDITURE ON: | | | | | | | |
| Charitable activities | 9(a) | 1,008,844 | 332,765 | 1,341,609 | 1,290,529 | 308,155 | 1,598,684 |
| Raising funds | 10 | 33,971 | 181,998 | 215,969 | 86,270 | 137,398 | 223,668 |
| | | | | | | | |
| Total | | 1,042,815 | 514,763 | 1,557,578 | 1,376,799 | 445,553 | 1,822,352 |
| | | | | | | | |
| Net income/ (expendit | ure) | | | | | | |
| before taxation | | (130,818) | 105,620 | (25,198) | 64,326 | 74,445 | 138,771 |
| | | | | | | | |
| Taxation | 11 | | | | | | |
| Net income/ | | | | | | | |
| (expenditure) | 13 | (130,818) | 105,620 | (25,198) | 64,326 | 74,445 | 138,771 |
| | | | | | | | |
| Transfers between | 21 | 34,592 | (34,592) | _ | 68,918 | (68,918) | _ |
| funds | 21 | | (34,392) | | 00,910 | (08,918) | |
| Not an origina ant in | | | | | | | |
| Net movement in funds | | (96,226) | 71,028 | (25,198) | 133,244 | 5,527 | 138,771 |
| Total funds brought | | (30,220) | 71,020 | (23,130) | 133,244 | 5,527 | 130,771 |
| forward | 21 | 200,408 | 1,396,381 | 1,596,789 | 67,164 | 1,390,854 | 1,458,018 |
| Total funds carried | | | , , | | | , -, | , , |
| forward | 21 | 104,182 | 1,467,409 | 1,571,591 | 200,408 | 1,396,381 | 1,596,789 |
| | - | | | | | | |

BALANCE SHEET AS AT 31 DECEMBER 2021

| | Notes | 2021 € | 2020 € |
|--|-------|-----------|-----------|
| Fixed Assets | | | |
| Tangible assets | 14 | 149,021 | 143,467 |
| Current Assets | | | |
| Stock | 15 | - | - |
| Debtors | 16 | 129,404 | 191,416 |
| Cash at bank and in hand | 17 | 1,444,814 | 1,443,251 |
| | | 1,574,218 | 1,634,667 |
| Current Liabilities | | | |
| Creditors: Amounts falling due within one year | 18 | (151,648) | (181,345) |
| Net Current Assets | | 1,422,570 | 1,453,322 |
| TOTAL NET ASSETS | 22 | 1,571,591 | 1,596,789 |
| | | | |
| FUNDS OF THE CHARITY: | | | |
| Restricted funds Unrestricted funds | 21 | 104,182 | 200,408 |
| - General funds | 21 | 929,387 | 858,359 |
| - Designated funds | 21 | 538,022 | 538,022 |
| TOTAL FUNDS | | 1,571,591 | 1,596,789 |

The financial statements were approved and authorised for issue by the Board of Directors on 24th May 2022 and signed on its behalf by:

Cathy Currede

Cathy Grieve Director

and Jalve

Paul Kehoe Director

STATEMENT OF CASH FLOWS FOR THE FINANCIAL YEAR ENDED 31 DECEMBER 2021

RECONCILIATION OF NET (EXPENDITURE)/INCOME TO CASH USED IN CHARITABLE ACTIVITIES

| | 2021 € | 2020 € |
|--|-----------|-----------|
| Net (expenditure)/income for the year | (25,198) | 138,771 |
| Adjustments for: | | |
| Depreciation | 34,890 | 23,219 |
| Decrease in debtors | 62,012 | (60,733) |
| Decrease in creditors | (29,697) | (56,426) |
| Net cash flows from operating activities | 42,007 | 44,831 |
| Cash flows from investing activities | | |
| Purchase of tangible assets | (40,444) | (20,303) |
| Net cash provided by investing activities | (40,444) | (20,303) |
| Change in cash and cash equivalents in the reporting year | 1,563 | 24,528 |
| Cash and cash equivalents at the beginning of the reporting year | 1,443,251 | 1,418,723 |
| Cash and cash equivalents at the end of the reporting year | 1,444,814 | 1,443,251 |
| Reconciliation to cash at bank and in hand: | | |
| Cash and cash equivalents at the end of financial year | 1,444,814 | 1,443,251 |

NOTES TO THE FINANCIAL STATEMENTS FOR THE FINANCIAL YEAR ENDED 31 DECEMBER 2021

1. ACCOUNTING POLICIES

The following accounting policies are applied consistently in dealing with items which are considered material in relation to the company's financial statements:

Basis of Preparation

The financial statements have been prepared under the historical cost convention, modified to include certain items at fair value, and in accordance with the Statement of Recommended Practice (SORP 2015)) "Accounting and Reporting by Charities" in accordance with the Financial Reporting Standard applicable in the UK (which has been recognised as best practice for financial reporting by charities in Ireland) and Republic of Ireland (FRS 102), issued by the Financial Reporting Council, and the Companies Act 2014.

Brainwave-The Irish Epilepsy Association T/A Epilepsy Ireland is a company incorporated in Ireland under the Companies Act 2014. The address of the registered office is 249 Crumlin Road, Dublin 12. The nature of the company's operations and its principal activities are set out in the Directors' Report on pages 3 to 18. In accordance with Section 1180(8) of the Companies Act, 2014, the company is exempt from including the word "Limited" in its name. The company is limited by guarantee and has no share capital. In prior years companies not trading for gain for the members were not within the scope of company law requirements with regard to formats and content of financial statements which applied to for profit companies thus permitting the adoption of a format appropriate to a charity. Accordingly, the company adopted and reported its performance in accordance with the format provided for in the Charities SORP and in particular reports its performance for the financial year in the format of the SORP's Statement of Financial Activities (SOFA).

The functional currency of Brainwave-The Irish Epilepsy Association T/A Epilepsy Ireland is considered to be euro because that is the currency of the primary economic environment in which the company operates.

Fixed Assets

Fixed assets are stated at cost less accumulated depreciation. Depreciation is charged at the following annual rates:

| Premises | : | 1% straight line |
|-------------------------------|---|----------------------|
| Fixtures and fittings | : | 20% straight line |
| Computer and office equipment | : | 33.33% straight line |

Financial Assets

Financial assets are stated at fair value and all gains and losses are recognised in the Statement of Financial Activities.

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED) FOR THE FINANCIAL YEAR ENDED 31 DECEMBER 2021

1. ACCOUNTING POLICIES (CONTINUED)

Retirement benefits

Retirement benefits for certain employees are funded by contributions from the company and the employees. Payments are made to a pension trust which is financially separate from the company. These payments are included in expenditure in the year in which they are paid. The scheme is a defined contribution scheme.

Income

Public donations and similar income arising from fundraising events are accounted for when received. As with many similar charitable organisations, independent groups from time to time organise fundraising activities. However, as amounts collected this way are outside the control of the company, they are not included in the financial statements until received by the company. Training Income is recognised when receivable.

Donations in kind represent goods or services provided to the charity free of charge. Where valuation can be measured with reasonable certainty, donations in kind are recognised in full as income in the year of receipt. Donations are valued at the cost to the donor or the amount normally chargeable by the donor for the goods or services provided. If such a valuation is not available, reasonable prevailing market rates are used. A matching expenditure is recognised when the goods or services are received.

Revenue Grants

Revenue grants received and receivable are credited to the Statement of Financial Activities on the basis of the allocated amount for that financial year.

Deferred Income

Deferred income represents monies received in advance in respect of specific projects to be undertaken in a future period.

This income will be released to the Statement of Financial Activities in the financial year in which the expenditure is incurred.

Fund Accounting

The following funds are operated by the Charity:

General Funds - unrestricted

General Funds represent amounts which are expendable at the discretion of the Board of Directors in furtherance of the objective of the charity which have not been designated for other purposes. Such funds may be held in order to finance working capital or capital expenditure.

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED) FOR THE FINANCIAL YEAR ENDED 31 DECEMBER 2021

1. ACCOUNTING POLICIES (CONTINUED)

Fund Accounting (Continued)

Designated Funds

Designated funds are unrestricted funds earmarked by the Board of Directors for particular purposes.

Restricted Funds

Restricted funds represent income, which has been received and recognised in the financial statements, which is subject to specific conditions imposed by the donors or grant making institutions.

Foreign Currencies

Transactions are recorded at the rates of exchange ruling at the date of transaction. Assets and liabilities denominated in foreign currencies are translated at the rate of exchange ruling at the balance sheet date. Foreign exchange profits and losses are dealt with in the statement of financial activities in the financial year in which they occur.

Financial Instruments

Financial assets and financial liabilities are recognised when the company becomes a party to the contractual provisions of the instrument. Financial liabilities are classified according to the substance of the contractual arrangements entered into.

(i) Financial assets and liabilities

All financial assets and liabilities are initially measured at transaction price (including transaction costs), unless the arrangement constitutes a financing transaction. If an arrangement constitutes a finance transaction, the financial asset or financial liability is measured at the present value of the future payments discounted at a market rate of interest for a similar debt instrument.

Financial assets are derecognised when and only when a) the contractual rights to the cash flows from the financial asset expire or are settled, b) the company transfers to another party substantially all of the risks and rewards of ownership of the financial asset, or c) the company, despite having retained some significant risks and rewards of ownership, has transferred control of the asset to another party and the other party has the practical ability to sell the asset in its entirety to an unrelated third party and is able to exercise that ability unilaterally and without needing to impose additional restrictions on the transfer.

Financial liabilities are derecognised only when the obligation specified in the contract is discharged, cancelled or expires.

Balances that are classified as payable or receivable within one year on initial recognition are measured at the undiscounted amount of the cash or other consideration expected to be paid or received, net of impairment.

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED) FOR THE FINANCIAL YEAR ENDED 31 DECEMBER 2021

2. GOING CONCERN

The financial statements have been prepared on the going concern basis.

The directors have considered and continue to monitor the impact of the Covid-19 pandemic on the company. Since early 2020, the pandemic has adversely affected the organisation's income-generating capacity as described above in the Director's Report.

The Board recognises the organisation's ongoing dependence on HSE and other state funding and supports to deliver its core services. Critically, HSE Service Level Agreements (SLAs) have been maintained at agreed levels since the beginning of the pandemic.

The organisation's other main sources of income are from fundraising activities and training services. While the latter recovered in 2021 to pre-pandemic levels, fundraising income was again significantly below historical performance due to the impact of restrictions on traditional fundraising activities.

The overall impact of the pandemic has been mitigated by accessing the Department of Rural and Community Development COVID-19 Stability Fund for Community and Voluntary, Charity and Social Enterprises. This funding has been utilised for eligible expenditure incurred prior to 30 June 2021. In addition, operational expenditure continued to be closely monitored by management and the Board and the company recorded a small deficit of €25,198 for the year.

The company has net current assets of €1.422m (2020: €1.453m), including €1.444m (2020: €1.443m) in cash at bank.

While the reserves position at year end means that there is no immediate threat to the going concern status of the company, the provision of services remains reliant on funding from the HSE continuing at the same or enhanced levels in the future.

Management and the Board have continued to update forecasts and projections, taking account of the anticipated impact and uncertainties of Covid-19 and other external factors. With Covid-19 restrictions lifting in early 2022, it is expected that fundraising performance will improve during the year and beyond. These forecasts, alongside the reserves held, mean the Board has a reasonable expectation that the company has adequate resources to operate within its current cash flows and reserves for the foreseeable future (at least twelve months from the date of approval of these financial statements).

Therefore, the Board continues to adopt the going concern basis of accounting in preparing the annual financial statements. Accordingly, these financial statements do not include any adjustments to the carrying amount and classification of assets and liabilities that may arise if the company was unable to continue as a going concern.

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED) FOR THE FINANCIAL YEAR ENDED 31 DECEMBER 2021

3. CRITICAL ACCOUNTING JUDGEMENTS AND KEY SOURCES OF ESTIMATION UNCERTAINTY

In the application of the company's accounting policies, which are described in note 1, the directors are required to make judgements, estimates and assumptions about the carrying amounts of assets and liabilities that are not readily apparent from other sources. The estimates and associated assumptions are based on historical experience and other factors that are considered to be relevant. Actual results may differ from these estimates. The estimates and underlying assumptions are reviewed on an ongoing basis. Revisions to accounting estimates are recognised in the period in which the estimate is revised if the revision affects only that period or in the period of the revision and future periods if the revision affects both current and future periods.

Critical judgment in applying the company's accounting policies

Other than consideration of going concern detailed in note 2 above, there are no other critical areas of judgment.

| | Restricted funds € | Unrestricted funds € | Total 2021 € | Total 2020 € |
|-------------------|--------------------------|----------------------------|--------------------|--------------------|
| Collections | - | - | - | 43,989 |
| Donations | 44,203 | 107,584 | 151,787 | 122,252 |
| Donations In Kind | 7,563 | - | 7,563 | 249,075 |
| Memberships | - | 15,277 | 15,277 | 27,857 |
| Legacies | - | 101,500 | 101,500 | - |
| | 51,766 | 224,361 | 276,127 | 443,173 |
| | | | | |

4. DONATIONS AND LEGACIES

A non-cash amount of €7,563 (2020: €249,075) is included under Restricted Donations, representing a donated service from Havas Media Group in relation to the promotion of a public awareness campaign for International Epilepsy Day 2021.

In accordance with our policy on working with pharmaceutical & medical device industries, Epilepsy Ireland discloses all contributions from this sector. In 2021, we received the following contribution which is included in donations:

- Neuraxpharm Ireland Ltd: €10,000 restricted grant for the development of Epilepsy Ireland's training programme in epilepsy awareness and the administration of buccal midazolam in 2022.

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED) FOR THE FINANCIAL YEAR ENDED 31 DECEMBER 2021

5. INCOME FROM CHARITABLE ACTIVITIES

| Restricted funds € | Unrestricted funds € | Total 2021 € | Total 2020 € |
|--------------------------|---|--|--|
| 749,153 | - | 749,153 | 754,884 |
| 78,068 | - | 78,068 | 77,968 |
| 11,415 | - | 11,415 | 46,892 |
| (19,253) | - | (19,253) | 258,310 |
| | | | 23,184 |
| - | 109,004 | 109,004 | 121,947 |
| - | 151,050 | 151,050 | 92,903 |
| 6,810 | | 6,810 | - |
| - | 6,311 | 6,311 | 3,817 |
| 826,193 | 266,365 | 1,092,558 | 1,379,905 |
| | funds € 749,153 78,068 11,415 (19,253) - - 6,810 - | funds funds € € 749,153 - 78,068 - 11,415 - (19,253) - - 109,004 - 151,050 6,810 - - 6,311 | funds funds 2021 € € € € 749,153 - 749,153 78,068 - 78,068 11,415 - 11,415 (19,253) - (19,253) - 109,004 109,004 - 151,050 151,050 6,810 - 6,311 |

6. OTHER TRADING ACTIVITIES

| | Restricted | Unrestricted | Total | Total |
|-----------------------|------------|--------------|---------|---------|
| | funds | funds | 2021 | 2020 |
| | € | € | € | € |
| Raffles and lotteries | 31,414 | 14,187 | 45,601 | 40,599 |
| Campaigns and appeals | - | 18,030 | 18,030 | 14,917 |
| Fundraising events | 2,624 | 82,625 | 85,249 | 47,690 |
| | 34,038 | 114,842 | 148,880 | 103,206 |

7. INVESTMENT INCOME

| | Restricted | Unrestricted | Total | Total |
|-----------------|------------|--------------|-------|-------|
| | funds | funds | 2021 | 2020 |
| | € | € | € | € |
| Interest income | - | 2,015 | 2,015 | 3,453 |

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED) FOR THE FINANCIAL YEAR ENDED 31 DECEMBER 2021

8. OTHER INCOME

| | Restricted funds € | Unrestricted funds € | Total 2021 € | Total 2020 € |
|----------------------|--------------------------|----------------------------|--------------------|--------------------|
| Miscellaneous income | - | 12,800 | 12,800 | 31,386 |
| | | 12,800 | 12,800 | 31,386 |
| | | | | |

9(a). EXPENDITURE ON CHARITABLE ACTIVITIES

| Activity | | Restricted funds € | Unrestricted funds € | Total 2021 € | Total 2020 € |
|--|-----------------------------|--------------------------|---|---|---|
| Information and support | | 521,110 | 140,234 | 661,344 | 648,385 |
| Training and education | | 211,320 | 120,485 | 331,805 | 313,763 |
| Awareness | | 122,514 | 38,150 | 160,664 | 430,136 |
| Advocacy | | 91,583 | 27,335 | 118,918 | 118,432 |
| Research | | 62,317 | 6,561 | 68,878 | 87,968 |
| | | 1,008,844 | 332,765 | 1,341,609 | 1,598,684 |
| | Activities Undertaken | Grant funding of | Support costs | Total | Total |
| | Directly | activities | (Note 9(b)) | 2021 | 2020 |
| | • | | | | 2020 |
| | € | € | € | € | € |
| Activity | € | € | | | |
| Activity Information and support | € 138,582 | € | | | |
| | - | € - - | € | € | € |
| Information and support | 138,582 | € - - | € 522,762 | € 661,344 | € 648,385 |
| Information and support Training and education | 138,582 42,183 | € - - - | € 522,762 289,622 | € 661,344 331,805 | € 648,385 313,764 |
| Information and support Training and education Awareness | 138,582 42,183 | € - - 15,328 | € 522,762 289,622 137,884 | € 661,344 331,805 160,664 | € 648,385 313,764 430,136 |
| Information and support Training and education Awareness Advocacy | 138,582 42,183 22,780 | - - - | € 522,762 289,622 137,884 118,918 | € 661,344 331,805 160,664 118,918 | € 648,385 313,764 430,136 118,432 |

*Awareness includes a non-cash donated service from Havas Media Group in relation to the promotion of a public awareness campaign for International Epilepsy Day 2020 and 2021 (See Note 4).

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED) FOR THE FINANCIAL YEAR ENDED 31 DECEMBER 2021

9(b). ANALYSIS OF SUPPORT COSTS

| | 2021 € | 2020 € | Basis of allocations |
|---|-----------|-----------|---|
| Fundraising activities - Staff costs (Note 10) | 161,788 | 125,933 | Fundraising from % time spent on activities |
| Charitable activities | | | |
| Charge for financial year Staff Costs | 007 250 | 055 773 | Utilization by staff time across E activities |
| | 887,259 | 855,772 | Utilisation by staff time across 5 activities |
| Rent | 35,038 | 32,395 | Utilisation by staff time across 5 activities |
| Maintenance & Repairs | 23,575 | 32,038 | Utilisation by staff time across 5 activities |
| Office Expenses | 67,637 | 83,634 | Utilisation by staff time across 5 activities |
| Finance & Governance | 46,441 | 34,673 | Utilisation of staff time across 5 activities |
| Depreciation | 34,890 | 23,220 | Utilisation by department across 5 activities |
| (Note 9a) | 1,094,840 | 1,061,732 | |
| | | | |
| Total | 1,256,628 | 1,187,665 | |
| | | | |

10. EXPENDITURE ON RAISING FUNDS

| | Restricted funds € | Unrestricted funds € | Total 2021 € | Total 2020 € |
|--|--------------------------|----------------------------|--------------------|--------------------|
| Raising donations, legacies, corporate donations and regular giving Fundraising activities – campaigns | 15,100 | - | 15,100 | 84,085 |
| appeals and events | 16,086 | 22,995 | 39,081 | 13,650 |
| Support costs (Note 9(b)) | 2,785 | 159,003 | 161,788 | 125,933 |
| | 33,971 | 181,998 | 215,969 | 223,668 |
| | | | | |

11. TAXATION

No charge to taxation arises due to the charitable status of the company. The company is registered as a charity with the Revenue Commissioners under CHY No. 6170.

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED) FOR THE FINANCIAL YEAR ENDED 31 DECEMBER 2021

| 12. | EMPLOYEES AND REMUNERATION | 2021 | 2020 |
|-----|---|-----------|---------|
| | Average number of persons employed | 25 | 25 |
| | | | |
| | Service delivery | 14 | 14 |
| | Fundraising | 5 | 5 |
| | Administration | 3 | 3 |
| | Training | 3 | 3 |
| | | 25 | 25 |
| | | | |
| | The staff costs comprise: | € | € |
| | Information & Support | 343,881 | 341,756 |
| | Training & Education | 190,730 | 182,659 |
| | Awareness | 91,012 | 82,409 |
| | Advocacy | 89,171 | 81,775 |
| | Research | 17,956 | 16,459 |
| | Administration | 135,471 | 123,436 |
| | Fundraising | 161,788 | 105,537 |
| | Other compensation costs | 4,167 | 5,367 |
| | | 1,034,176 | 939,398 |
| | Included in the above are costs as follows: | | |
| | Employer's PRSI | 96,055 | 86,450 |
| | Retirement benefits (note 23) | 57,426 | 50,415 |
| | | | |

The number of employees whose salaries (excluding employer PRSI and pension contributions) were greater than €60,000 were as follows:

| | 2021 Number | 2020 Number |
|-------------------|----------------|----------------|
| €60,001 - €70,000 | 1 | 1 |
| €70,001 - €80,000 | - | - |
| €80,001 - €90,000 | 1 | 1 |
| | | |

The total remuneration for key management personnel for the financial year amounted to €186,417 (2020: €172,194). Remuneration includes salaries, employer PRSI and pension contributions.

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED) FOR THE FINANCIAL YEAR ENDED 31 DECEMBER 2021

| 13. | NET INCOME/(EXPENDITURE) | 2021 € | 2020 € |
|-----|--|-----------|-----------|
| | The net income/(expenditure) for the financial year is arrived at after charging/(crediting): Directors' remuneration and emoluments | _ | _ |
| | Depreciation | 34,890 | 23,219 |
| | Operating lease payments | 23,004 | 16,680 |
| | Bank deposit interest | (2,015) | (3,453) |
| | | | |

| 14. | FIXED ASSETS | Premises € | Fixtures and fittings € | Computer and office equipment € | Total € |
|-----|---------------------------|---------------|-------------------------------|--|------------|
| | Cost: | | | | |
| | At 1 January 2021 | 122,470 | 58,454 | 88,213 | 269,137 |
| | Additions | - | 2,085 | 38,359 | 40,444 |
| | Disposal/write downs | - | - | (22,102) | (22,102) |
| | At 31 December 2021 | 122,470 | 60,539 | 104,470 | 287,479 |
| | Depreciation: | | | | |
| | At 1 January 2021 | 16,375 | 43,073 | 66,222 | 125,670 |
| | Charge for financial year | 1,225 | 5,666 | 27,999 | 34,890 |
| | Disposal/write downs | - | - | (22,102) | (22,102) |
| | At 31 December 2021 | 17,600 | 48,739 | 72,119 | 138,458 |
| | Net Book Amount: | | | | |
| | At 31 December 2021 | 104,870 | 11,800 | 32,351 | 149,021 |
| | At 31 December 2020 | 106,095 | 15,381 | 21,991 | 143,467 |
| | | | | | |

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED) FOR THE FINANCIAL YEAR ENDED 31 DECEMBER 2021

| 15. | STOCK | 2021 € | 2020 € |
|-----|--------------------------------|-----------|-----------|
| | Stock of fundraising materials | - | - |

There are no material differences between the replacement cost and the balance sheet amounts.

| 16. | DEBTORS: Amounts falling due within one year | 2021 € | 2020 € |
|-----|---|-----------|-----------|
| | Debtors | 76,899 | 74,586 |
| | Prepayments | 37,233 | 25,108 |
| | Accrued income | 15,272 | 91,722 |
| | | 129,404 | 191,416 |
| 17. | CASH AT BANK AND IN HAND | 2021 | 2020 |
| | | € | € |
| | Cash at bank and in hand | 1,444,814 | 1,443,251 |
| | | 1,444,814 | 1,443,251 |
| | | | |
| 18. | CREDITORS: Amounts falling due within one year | 2021 | 2020 |
| | | € | € |
| | Creditors | 39,433 | 69,658 |
| | Accruals | 29,822 | 43,410 |
| | Deferred income (Note 19) | 41,363 | 42,937 |
| | PAYE/PRSI/USC | 21,777 | 25,340 |
| | Other Creditors | 19,253 | - |
| | | 151,648 | 181,345 |
| | | | |

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED) FOR THE FINANCIAL YEAR ENDED 31 DECEMBER 2021

19. DEFERRED INCOME

Deferred income comprises of grants for specific service delivery projects carried out by the Epilepsy Ireland. This income is released as the associated project costs are incurred for the relevant project.

| | 2021 € | 2020 € |
|--|------------------------------|------------------------------|
| Balance at start of financial year Amount received in the financial year Amount released to income in the financial year | 42,937 41,363 (42,937) | 45,117 41,435 (43,615) |
| Balance at end of financial year (Note 18) | 41,363 | 42,937 |
| | | |

20. FINANCIAL INSTRUMENTS

The carrying value of the company's financial assets and liabilities are summarised by category below:

| | 2021 € | 2020 € |
|--|-----------|-----------|
| Financial assets | | |
| Measured at undiscounted amounts receivable Debtors (Note 16) | 76,899 | 74,586 |
| | | |
| Financial liabilities | | |
| Measured at undiscounted amount payable Creditors (Note 18) | 39,433 | 69,658 |
| | | 00,000 |

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED) FOR THE FINANCIAL YEAR ENDED 31 DECEMBER 2021

21. ANALYSIS OF FUNDS

| | Opening balance 1 January 2021 € | Incoming resources € | Resources expended € | Transfers € | Closing balance 31 December 2021 € |
|---|--|----------------------------|----------------------------|----------------|--|
| Restricted funds | ť | e | e | e | C |
| Health Service Executive | 15,970 | 749,153 | (788,239) | 34,592 | 11,476 |
| SSNO Scheme | 936 | 78,068 | (69,595) | - 34,352 | 9,409 |
| SlainteCare Implement. Fund | 47,571 | 11,415 | (57,782) | _ | 1,204 |
| The Community Foundation | 23,184 | - | (15,083) | _ | 8,101 |
| DRCD COVID-19 Stability Fund | 95,222 | (19,253) | (68,494) | - | 7,475 |
| Havas in-kind donation | | 7,563 | (7,563) | - | - |
| Research funding | - | 31,414 | (31,414) | - | - |
| In Memory fundraising | - | 36,827 | - | - | 36,827 |
| Other Grants | 17,525 | 16,810 | (4,645) | - | 29,690 |
| | 200,408 | 911,997 | (1,042,815) | 34,592 | 104,182 |
| Unrestricted funds | | | | | |
| Operational Reserve | 858,359 | 620,383 | (514,763) | (34,592) | 929,387 |
| Designated Funds | | | | | |
| - Premises reserve | 100,000 | - | _ | - | 100,000 |
| - Research reserve | 188,022 | - | - | - | 188,022 |
| - Awareness campaigns | 100,000 | _ | - | - | 100,000 |
| Aids and Appliances Strategic Plan | 50,000 | - | - | - | 50,000 |
| Implementation | 100,000 | - | - | - | 100,000 |
| | 538,022 | | | <u>-</u> | 538,022 |
| TOTAL FUNDS | 1,596,789 | 1,532,380 | (1,557,578) | - | 1,571,591 |

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED) FOR THE FINANCIAL YEAR ENDED 31 DECEMBER 2021

21. ANALYSIS OF FUNDS (CONTINUED)

HSE-funded services are only partially funded and €34,592 (2020: €68,918) has been transferred from the unrestricted Operational Reserve to meet the full cost of providing the services.

€11,476 of HSE funds (2020: €15,970), made up predominantly of National Lottery grants and €9,409 of SSNO funds (2020: €936) are being carried forward for use in 2022.

The balances on the Slaintecare Implementation fund ($\leq 1,204$) and the Community Foundation ($\leq 8,101$) relate to depreciation charges to be incurred in future years. The balance on the Covid-19 Stability Fund ($\leq 7,475$) relates to pre-paid costs on grant expenditure incurred.

Other restricted grants totalling $\leq 29,690$ (2020: $\leq 17,525$) are also carried forward to be utilised in 2022. In-Memory fundraising of $\leq 36,827$ (2020: $\leq Nil$) relates to funds raised in 2021 specifically for the purpose of launching a new service to provide wearable seizure-monitoring devices to service users.

The Board has designated reserves for utilisation in special strategic activities including undertaking epilepsy awareness campaigns; providing funding for current and future research projects; providing and sustaining an expanded Aids & Appliances scheme; and for upgrading/relocating the charity's head office in Crumlin. The Board also maintains a reserve to facilitate implementation of the organisation's Strategic Plans. There were no changes to designated reserves in 2021.

22. ANALYSIS OF NET ASSETS BETWEEN FUNDS

| | Restricted Funds € | Unrestricted Funds € | Closing Balance € |
|---|--------------------------|-----------------------------------|-----------------------------------|
| Fixed assets Current assets Liabilities | - 104,182 - | 149,021 1,470,036 (151,648) | 149,021 1,574,218 (151,648) |
| | 104,182 | 1,467,409 | 1,571,591 |
| | | | |

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED) FOR THE FINANCIAL YEAR ENDED 31 DECEMBER 2021

22. ANALYSIS OF NET ASSETS BETWEEN FUNDS (CONTINUED)

| In respect of prior year | | | |
|--------------------------|------------|--------------|-----------|
| | Restricted | Unrestricted | Closing |
| | Funds | Funds | Balance |
| | € | € | € |
| Fixed assets | - | 143,467 | 143,467 |
| Current assets | 200,408 | 1,434,259 | 1,634,667 |
| Liabilities | - | (181,345) | (181,345) |
| | 200,408 | 1,396,381 | 1,596,789 |
| | | | |

23. RETIREMENT BENEFITS

The company operates a defined contribution scheme. The assets of the scheme are held separately from those of the company in an independently administered fund. The pension cost €57,426 (2020: €50,415) is charged to the Statement of Financial Activities in the financial year in which it arises. There was €8,681 payable at the financial year-end (2020: €9,189).

24. CONSTITUTION

The company is limited by guarantee and does not have a share capital. Every member of the company undertakes, if necessary during the time they are a member or within one year after they cease to be a member, to contribute to the assets of the company an amount not exceeding €1.

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED) FOR THE FINANCIAL YEAR ENDED 31 DECEMBER 2021

25. **COMMITMENTS**

The company has committed to spending the following on research projects in the coming years:

| | 2021 € | 2020 € |
|---|-----------|-----------|
| Within one year Between two and five years | 15,328 | - |
| | | |

Operating lease commitments

Total future minimum lease payments under non-cancellable operating leases are as follows:-

| | 2021 | 2020 |
|---|--------|-------------|
| | € | € |
| - Within 1 year | 31,410 | 11,890 |
| Between one and two years Between two and five years | 33,875 | 11,400 - |

26. **RELATED PARTY TRANSACTIONS**

There were no related party transactions in 2021.

27. SUBSEQUENT EVENTS

There are no significant events subsequent to the financial year end.

28. **COMPARATIVE AMOUNTS**

Certain comparative amounts have been reclassified, where necessary, to ensure comparability with current financial year disclosure.