

Brainwave-The Irish Epilepsy Association
T/A Epilepsy Ireland

Reports and Financial Statements
for the financial year ended
31 December 2019

**BRAINWAVE-THE IRISH EPILEPSY ASSOCIATION
T/A EPILEPSY IRELAND**

**REPORTS AND FINANCIAL STATEMENTS
FOR THE FINANCIAL YEAR ENDED 31 DECEMBER 2019**

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**BRAINWAVE-THE IRISH EPILEPSY ASSOCIATION
T/A EPILEPSY IRELAND**

DIRECTORS AND OTHER INFORMATION

DIRECTORS

Ms C. Grieve (Chairperson)
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Mrs T. Dagge
Mr M. Dowdall
Ms M. Fitzsimons
Mr D. Gray
Mr A. Kealy
Mr P. Kehoe
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SOLICITORS

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CHARITY NUMBER

CRA (Charities Regulator): 20010553
CHY (Revenue): 6170

**BRAINWAVE-THE IRISH EPILEPSY ASSOCIATION
T/A EPILEPSY IRELAND**

DIRECTORS' REPORT

The directors present their annual report and the audited financial statements of the company for the financial year ended 31 December 2019.

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. Epilepsy Ireland's vision is to achieve a society where no person's life is limited by epilepsy.

Epilepsy affects at least 37,000 people in Ireland, which makes it one of the most common neurological conditions. It affects people of all ages, including an estimated 10,000 children under the age of 16. There are an estimated 1,300–2,100 new diagnoses each year in Ireland. Approximately 10,000–15,000 people are living with uncontrolled seizures and for this group in particular, the consequences of an epilepsy diagnosis can be long-lasting and significant. It can affect the person's 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, predominantly as a result of sudden unexpected death in epilepsy (SUDEP) and status epilepticus (prolonged seizures). Epilepsy can also have serious psychological, social and economic consequences for families and carers.

2019 was the third year of Epilepsy Ireland's 2017-2021 Strategic Plan. The Plan contains 21 strategic objectives, grouped under six overarching aims, which focus on our core areas of work:

- 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.

The Directors' acknowledge that the 2017-2021 Plan is ambitious and that resourcing full implementation of the 21 strategic objectives presents real challenges. The organisation is committed to protecting and maintaining existing services and activities, while also developing in new directions to ensure we continue to meet the needs of people with epilepsy and their families in Ireland.

DIRECTORS' REPORT (CONTINUED)

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.

Epilepsy Ireland provides a range of support services including one-to-one support, educational programmes, support groups, individual and group-based self-management programmes, community and hospital-based outreach services and a nurse-led helpline. Our staff team also develop and coordinate local seminars, family days, workshops and events in addition to producing a range of resources and publications.

Our services are provided by a team of 11 Community Resource Officers (CROs) based in Dublin, Cork, Galway, Limerick, Kilkenny, Killarney, Tullamore, Letterkenny/Sligo and Dundalk. In addition, services are provided by the National Information Officer and through Epilepsy Ireland-funded nursing posts.

As has been the case in most recent years, during 2019 the demand for our services increased on the previous year. We recorded an increase in individual contacts with services users from 19,447 in 2018 to 21,821 in 2019. One-to-one contacts with our CROs, Information Officer, Training Manager and Epilepsy Nurses totalled 11,984 in 2019 (2018: 9,794). Contacts with individuals in group settings including educational/ awareness sessions, group self-management and training programmes totalled 9,837 in 2019 (2018: 9,653). We worked with 2,774 new service users in 2019 (2018: 2,449).

An important core service is the Living Well with the Epilepsy 'Toolkit' Programme. This programme is aimed at individuals/ parents of children with a new diagnosis of epilepsy. In 2019, 300 people completed the programme (2018: 545). Since it was developed in 2014, we have now delivered the programme with almost 2,300 individual service-users.

Our CRO team also facilitate group-based self-management programmes for adults and parents. These group-based programmes include Support and Training in Epilepsy Self-management (STEPS) and Parents STEPS. These programme enable people to learn more about epilepsy and the tools and knowledge to become experts in managing their own epilepsy. We also provide an advanced self-management programme called Innerwise, which focuses on improving mental health and wellbeing, managing stress and developing life management skills through tools such as mindfulness and meditation. A total of 9 self-management programmes were run across the country in 2019 (2018: 20).

Reduced demand for these programmes highlights a growing need for more personalised and one-to-one supports, in part as a result of increasing complexity in individual support cases, as noted in previous years. It is also a function of a strategic shift in focus to working more in partnership with HSE hospital services in recent years. Data from the Epilepsy Partnership in Care (EPIC) study on patient centred care in epilepsy was published in 2019. The study, led by RCSI and NUI Maynooth highlighted the importance of developing collaboration between Epilepsy Ireland CROs and hospital-based epilepsy specialist nurses, and the benefits that would accrue for patients with epilepsy. Active participation in this research has helped develop stronger links and collaborative efforts between Epilepsy Ireland and HSE epilepsy services in recent years.

We continue to support hospital-based epilepsy services by receiving referrals for one-to-one supports from Epilepsy Specialist Nurses (ESNs), Neurologists and Paediatric Neurology teams and through our hospital outreach activities. Education sessions delivered jointly by CROs and HSE ESNs continue to be an important service delivered on-site at epilepsy clinics. There were 70 sessions held in hospital settings in 2019 (2018: 68) with 412 (2018: 413) patients availing of this support.

Funding of over €93,000 to expand this hospital-based work was secured in 2019 through the Sláintecare Integration Fund. This funding will enable Epilepsy Ireland to work with partners in hospital settings to jointly deliver an education programme to those with a new diagnosis of epilepsy. The 'Joint Education Sessions' will be piloted in five Dublin hospitals starting in November 2019. An additional element will be the development of a patient-held Checklist and training materials with the aim of providing individuals with established epilepsy the tools to be more prepared and proactive in their primary care appointments.

BRAINWAVE-THE IRISH EPILEPSY ASSOCIATION T/A EPILEPSY IRELAND

DIRECTORS' REPORT (CONTINUED)

Epilepsy Ireland has a long history of supporting epilepsy nursing posts in the health service and in 2019, the funded candidate Advanced Nurse Practitioner (cANP) post at Beaumont hospital became a registered ANP (rANP), with a focus on 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. The rANP also provides specialised epilepsy advice and support to Epilepsy Ireland CROs and National Information Officer, participates in workshops, talks and seminars and contributes to Epilepsy Ireland publications.

We also continued to fund the Epilepsy Transition Coordinator post with the Children's Hospital Group to the completion of a three-year project in May 2019. Epilepsy Ireland's support over three years led to the setting up of dedicated transition services in Beaumont and St. James's hospitals, the establishment of a transition registry and the development of transition pathways from children to adult services.

Regional support groups are facilitated by CROs across the country, providing an informal opportunity to share information, offer and receive mutual support. In 2019 there were 61 support group events (2018: 51) with 493 (2018: 553) people attending.

We also aim to work with and support teens and young adults with epilepsy. In 2019, a short radio skills programme was piloted with Near FM in Dublin. In addition, two art-based workshops were organised for siblings of young people with epilepsy. One group was specifically for teens while the other was for siblings aged 7 to 11 years. The groups were facilitated by SibShops in Dublin and Meath.

Three young people with epilepsy were nominated by Epilepsy Ireland to participate in an international advocacy & communications workshop organised by the International Bureau for Epilepsy (IBE). Our annual family fun day took place in July at Dublin Zoo with over 200 people participating, while smaller regional family events took place in Kerry and Limerick during the year.

The 2019 National Epilepsy Conference took place in Cork in September with over 200 people attending to learn about the latest developments in epilepsy care, research and services and to take part in epilepsy workshops. Following on from successful events in 2018, two 'Heads-Up' conferences we held in March in Limerick and Meath. These events focused on issues around memory, cognition and mental wellbeing for adults with epilepsy and were originally developed in response to feedback from our service users. Other notable events included three workshops on issues arising for women with epilepsy, held in Galway, Kilkenny and Cork. We also assisted with an international policing seminar held in Dublin, highlighting epilepsy awareness and responding to seizures to a key target audience.

We continually review and update our epilepsy information materials and in 2019, revised resources published by Epilepsy Ireland included 'Epilepsy Explained, Frequently Asked Questions', 'Safety and Seizures' and 'Epilepsy and Children, A Guide for Parents'. We also worked to distribute our epilepsy guide for teachers and educators, launched in late 2018.

Our epilepsy.ie website remains a key source of accurate, trusted and up-to-date information and news for all our stakeholders and the general public. Our social media channels (Facebook, Twitter, Instagram and YouTube) are also vital to our work in communicating our activities and news to followers.

Facebook followers increased from 14,000 to almost 16,000 enabling us to reach a total of over 1.9m people during the year. Our Twitter followers grew by 10% to 4,400 while on Instagram, we grew by 25% to over 2,000 followers. Our Smartphone Epilepsy Management app enables users to record and track seizures, get medication reminders and manage information for medical appointments among other features to support people with epilepsy and parents of children with the condition. The app was also updated in 2019.

Epilepsy Ireland is a membership-based organisation and in 2019, we put in place a new membership strategy to recruit and retain members. This followed a restructuring of our membership packages in 2018, and included incentives such as a new range of discounts for members. Members continue to receive safety pillows and/or epilepsy wristbands upon joining.

DIRECTORS' REPORT (CONTINUED)

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.

Epilepsy Ireland organises or participates in a number of national and international opportunities to communicate with our target audiences and raise awareness of epilepsy.

International Epilepsy Day is celebrated annually on the second Monday of February to help promote better public understanding of the condition globally. In 2019, Epilepsy Ireland used the day to focus on seizure awareness with Ireland Rugby Head Coach, Joe Schmidt supporting the TEAM campaign:

T – Take care to protect the person

E – Ensure you stay with them

A – Allow the seizure to run its course

M – Move the person onto their side when the seizure is over

The message was promoted online and in the media, supported with a short radio advertising campaign. Joe Schmidt has been an active and high-profile ambassador for epilepsy in recent years, and one of his final engagements as Ireland Head Coach was the annual fundraising lunch in May alongside Kathryn Thomas, BJ Botha and Epilepsy Ireland Patron Rick O' Shea.

BJ Botha also got involved in #EpilepsyDay, talking about his family's experience of living with epilepsy in the media. There was widespread local and national media coverage of the day as well as a strong social media interest where #EpilepsyDay trended at number one in Ireland and reached >100,000 people on Facebook.

Purple Day, which takes place on March 26th annually is becoming a key awareness and fundraising event for Epilepsy Ireland. In 2019, there were dozens of coffee mornings held by supporters around the country, Purple Day wristbands were available for purchase in 50 different locations, while a host of schools and companies were involved in fundraising activities using the colour purple. Epilepsy Ireland Patron Rick O'Shea and consultant neurologist Dr. Peter Widdess-Walsh appeared on Ireland AM to discuss epilepsy. Almost 40 well known buildings and landmarks across Ireland also lit up purple that evening to mark the occasion. These included Dublin City Hall, Eyre Square, the National Convention Centre and Kilkenny Castle.

Brain Awareness Week in March was co-ordinated by the Neurological Alliance of Ireland (NAI) and all Epilepsy Ireland regional offices organised events during the week. The NAI's Love Your Brain campaign aimed to promote greater awareness and understanding of the brain and brain conditions as well as the need for more investment in services, research and disease prevention. Love your Brain was supported by over 20 patient organisations including Epilepsy Ireland.

National Epilepsy Week in May focused on local events including events for teachers, community engagement events and public information stands. International SUDEP Day was held in October and Epilepsy Ireland participated by reaching out to members, service users and the public to inform about SUDEP and also on the critical issue of managing epilepsy risks.

Other activities of note during the year included partnering with Cork Airport in epilepsy awareness training for staff as part of their strategy to assist passengers with hidden disabilities and working more closely with An Garda Síochána to highlight epilepsy awareness.

In terms of epilepsy advocacy, it was another busy year. Following a successful and sustained effort in 2018, work continued on the sodium valproate/ foetal anti-convulsant syndrome (FACS) campaign alongside OACS (Organisation for Anti-Convulsant Syndrome) Ireland focusing on three main issues: reducing the risks of FACS; seeking services for families affected by in-utero valproate exposure; and establishing an independent investigation into the historical use of Valproate in Ireland. We continued to work for the implementation of the Oireachtas Health Committee's 12 recommendations published in 2018. Following the completion of the HSE's Valproate Response Project, we were due to revisit the Committee in early 2020 to highlight the need for action on outstanding issues such as vacant nursing posts, access to diagnostics and family support packages. However, this was postponed to a later date following the dissolution of Dáil Éireann.

DIRECTORS' REPORT (CONTINUED)

A highlight of the advocacy campaign in 2019 was the "National Conference on the Consequences of Sodium Valproate (Epilim): 50 years on", held in Trinity College in March. The event was jointly organised by the HSE, Epilepsy Ireland and OACS Ireland and attended by patients & families affected by valproate, healthcare professionals and policy makers. It featured presentations from a range of experts from the UK and Ireland in addition to the experiences of families affected and updates on the Irish response to the valproate problem to date.

Other advocacy-related issues during the year included:

- Access to free travel for people with epilepsy who are prohibited from driving – this long-running campaign received a boost when the Oireachtas Health Committee supported the campaign in July. The Board also approved funding for a small study on the impact of driving cessation to be undertaken at Beaumont Hospital.
- Through an internal working group, work began on the development of an epilepsy advocacy 'manifesto' for Ireland. We consulted with members on the key epilepsy advocacy issues affecting them and at year end, we were in the process of organising focus groups to consult further as well as reaching out to the medical community.
- Access to medications was also a common theme during the year; including the impact of Brexit; the Government's steps to introduce the Medical Cannabis Access Programme; and the re-emerging issue of generic substitution/ interchangeability. We also signed the IPPOSI Patient Charter, a call to review patient involvement in the processes of assessing and reimbursing new medicines.
- We also continued to work closely with medical professionals through the HSE's National Epilepsy Clinical Care Programme, the Epilepsy Electronic Patient Record steering group, the Irish Epilepsy League and the Irish Epilepsy Nurses Group. Effective advocacy is also carried out in conjunction with representative groups such as the Disability Federation of Ireland, the Neurological Alliance of Ireland, The Wheel, Charities Institute Ireland, Health Research Charities Ireland and the International Bureau for Epilepsy.

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

Training for Success (TFS) is a one-year full-time QQI Level 5 course based in the Institute of Technology Sligo and funded by the Mayo, Sligo and Leitrim Education and Training Board (MSLETB). This unique one-year course was first established in 1998 as a pre-employment qualification and this element has continued to be an integral component of the course. Today the course also works to make education more easily accessible to people with epilepsy who, due to their condition have experienced difficulties in the progression of their educational and career aspirations.

The variety of employment, training and education options in recent years has brought challenges for course recruitment and seven students began the 2018/19 programme, of whom five graduated in 2019. The TFS Programme Manager retired in November 2019 and programme staffing was reconfigured to meet the changing environment. During 2019, we continued to work with TFS partners on recruitment and sustainability measures and 10 students from around the country were welcomed to TFS for the 2019/2020 programme.

Since 2009, Epilepsy Ireland has been providing a training programme in Epilepsy Awareness & the Administration of Buccal Midazolam (BM) to health professionals and allied health professionals. The aim of the training programme is for participants to develop a greater understanding of epilepsy in general, understand the role of the emergency rescue medication and receive instruction in the correct administration of BM.

We witnessed continued growth in the demand and delivery of the training during the year. 277 one-day training sessions were delivered in 2019 (2018: 199). There was also significant growth in the number of trainees which increased from 2,146 in 2018 to 2,871 in 2019, an increase of 33%. EI has many long-standing clients who regularly access the training while new client organisations include a large number of those involved in home care delivery.

The courses are delivered nationwide by Epilepsy Ireland's Training Manager and by our CRO network. Evaluation of the programme and in particular the extent to which participants' knowledge/ skills have improved or increased as a result of the course continue to show a high degree of satisfaction with the programme. In 2019, 94% strongly-agreed or agreed that the programme has improved their ability to deal with the emergency response involving the administration of BM for prolonged/ serial seizures.

DIRECTORS' REPORT (CONTINUED)

We also provide demonstrations for parents and carers in administering BM. In 2019, 231 parents/ carers attended demonstrations (2018: 128) and we hope to expand this critical service in 2020 and future years.

2019 was another typically busy year for the Schools Education Programme. This programme aims to raise awareness of epilepsy for those with the responsibility for ensuring a safe education environment. The programme typically includes an introduction to epilepsy; a brief classification of seizure activity; and most importantly, steps that should be taken and avoided in responding to seizures at school. In 2019 4,659 teachers, SNAs and students attended 156 training days nationwide (2018: 146).

Off-site Epilepsy Awareness Presentations for Teachers and SNAs are also organised by Epilepsy Ireland and in 2019, 21 events were held nationwide with a further 640 professionals attending these evening programmes (2018:16/~400).

We also provide epilepsy awareness presentations to various groups that include employers, training organisations, community groups etc. There was a significant increase in this activity in 2019, with a total of 114 presentations delivered, attended by 2,745 people (2018: 62/1,050).

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.

Epilepsy Ireland operates a Research Funding Scheme to provide epilepsy researchers in Ireland with an avenue to access funding for quality, high-impact research.

Three Epilepsy Ireland funded projects continued throughout 2019.

Prof David Henshall's study at RCSI on the role of microRNAs in the mechanism of the ketogenic diet is investigating whether microRNA levels in blood samples or other body fluids (urine, saliva) can predict which children will benefit most on the diet and aims to shed new light on how the diet works. This study was initially funded in 2016 under the HRB/HRCI Joint Funding scheme. Prof. Gianpiero Cavalleri is investigating, also at RCSI, possible links between auto-immune epilepsy and the microbiome. This study was funded for three years from 2018 also under the HRB/HRCI Joint Funding Scheme.

We also continued to co-fund research at RCSI on the role of the Epilepsy Patient Portal in improving epilepsy health services. The study measures patient, carer and healthcare professional perspectives on the e-Portal, an e-health solution which allows epilepsy patients to access and interact with their own health records online. The project is funded by the HRB under the Applied Partnership Awards. €20,000 is being provided by Epilepsy Ireland as a knowledge-user.

In 2019, the Board approved the launch of Epilepsy Ireland's seventh call for funding proposals. A record 16 pre-applications were received by the deadline and by the end of 2019, a shortlisting process had been completed by the Research Review committee chaired by Prof Martin Brodie which resulted in six applicants being invited to submit full applications.

Prior to launching the research call, we surveyed our members and service users about the key priorities for funding. Feedback from almost 100 people was received and the Board agreed to issue the 2019/20 call focusing on the key themes identified in the feedback: SUDEP; Cannabinoids; Epilepsy and intellectual disability; Technology/Assistive Technology; Rare/Complex epilepsy; Pregnancy and epilepsy; Diet & nutrition in epilepsy; and Psychosocial aspects of epilepsy. Applications of up to €50,000 p.a. for up to three years were invited and the process continues into 2020 when the Research Review Committee will reconvene to make funding recommendations to the Board.

Epilepsy Ireland has invested over €1 million in 13 projects since 2009 under our Research Funding Scheme. The scheme has supported a wide range of relevant research questions including epilepsy genetics, molecular mechanisms of epilepsy, sudden unexpected death in epilepsy, stigma, family communications, epilepsy specialist nurses, biomarkers, seizure dogs and e-health in epilepsy. In 2019, we marked the €1m milestone through a video featuring funded researchers and people with epilepsy and through the hosting of a special "Epilepsy Research Explained" public event with FutureNeuro, attended by over 200 people on International Epilepsy Day. We also collaborated with Trinity College Dublin on a further public event on epilepsy research for the Festival of Neuroscience in April.

DIRECTORS' REPORT (CONTINUED)

Other research communications activities during the year included the publication of our research newsletter for donors who support research funding and collaborating with FutureNeuro on the 'Epilepsy in English' website aimed at explaining epilepsy research in plain English for a public audience.

Epilepsy Ireland also supports Irish research in a number of non-financial ways. We highlight research volunteering opportunities to our service users. For example, in 2019, this included research at Queens University Belfast on the role that untrained pet dogs can have in predicting seizures.

We also work with research teams as an official collaborator where possible. In 2019, this included the ongoing DCU Patient & Public Involvement (PPI) Ignite project; a HRB-funded study into the effectiveness of risk minimisation measures to prevent harm from teratogenic medicines in pregnancy; and a newly funded HRB proof of concept study which will look at the potential to link data from sources such as the epilepsy electronic patient record to other data sources like the PCRS to gain insights into disease progression, risks and resource utilisation. Epilepsy Ireland staff are also contributing to the various stages of the e-Portal project in our role as project knowledge-user.

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 HSE Service Level Agreements (SLAs) with Community Healthcare Organisations (CHOs) across the country. These agreements support posts and costs relating to many of our support, education and information activities. However, a series of historical funding cuts combined with increasing costs and rising demand for our services has meant that in recent years, HSE funds are not sufficient cover the cost of the services provided.

Following the publication in 2019 of the Report of the Independent Review Group established by the Minister for Health to examine the relationship between the voluntary sector and the state, Epilepsy Ireland accepted an invitation to address the Oireachtas Health Committee on the issue of Section 39 funding for voluntary organisations. We highlighted the role of community-based organisations like Epilepsy Ireland and called for the urgent implementation of the Report's recommendations to address issues around the adequacy of Section 39 funding and a range of other measures.

In 2019, there was a funding shortfall of €90,686 (2018: €150,975), which has been met by a combination unrestricted fundraising income, tight cost control and where required by utilising unrestricted reserves. We also worked to reduce the shortfall in 2019 by successfully sourcing new grant income through the Scheme to Support National Organisations (SSNO) and the Slaintecare Integration Fund. Total grant income in 2019 (including HSE, MSLETB, SSNO, Slaintecare and other grants) was €937,696 (2018: €874,553).

Total non-grant income in 2019 was €797,892 (2018: €1,171,496), which was in line with expectations, following an extremely successful year where income was boosted significantly by two large, one-off sources of income. Income generation activities in 2019 again enabled the Board to meet HSE deficits from the current year income, while recording a small operational surplus.

Income generating activities include a range of fundraising events such as national church gate collections, the Rose Week Appeal, Purple Day the annual fundraising lunch, our members raffle and the Time for a Break monthly draw. Our supporters take part in events like the Women's Mini Marathon and other events and challenges around the country, while others generously make donations or invest their time and skills in organising events. Corporate supports and legacy donations have also become an important part of the fundraising mix in recent years, while earned income, predominantly from training services has grown in importance.

The Board remains acutely aware of the risks associated with income generation and sustainability (see Risks and Uncertainties below). In 2019, the Board established the Business Development & Sustainability sub-committee to assist, support and advise the Board in ensuring that the organisation's income generation activities are sufficient to meet the financial, strategic and operational needs of the organisation into the future.

DIRECTORS' REPORT (CONTINUED)

Operationally, the organisation also invested in additional staff resources in fundraising which led in part to a small increase to in the cost of raising funds to €329,643 in 2019 (2018: €312,121)

Details of the organisation's Reserves and movements during 2019 are outlined in Note 21 to the accounts.

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 AND MANAGEMENT

The Epilepsy Ireland voluntary board of directors are committed to the highest standards of corporate governance and understand that this is a key obligation in ensuring best practice in the operation of the organisation's activities.

Central to this is the board membership which has the appropriate skills and experience and has an effective executive. The board is comprised of 12 volunteer members (as at 31-12-2019) drawn from a variety of backgrounds and experiences and is responsible for the leadership, strategy and control of the organisation. Six directors stepped down from the board during 2019 following many years of service. These were: Prof Norman Delanty, Dr Michael Hennessy, Dr Brian McNamara, Dr Brian Sweeney, Dr Bryan Lynch and Mr Michael McLoughlin. Other changes during the year included the appointment of Ms Cathy Grieve as Chairperson, replacing Mr Mark Dowdall who served as Chair for six years. Ms Clare O'Dea was elected as Company Secretary to replace Ms Grieve.

The board governs the organisation in accordance with its constitution, which was last reviewed and approved by members in 2017. The board operates within the context of the organisation's Strategic and operational plans and with reference to budgets reviewed by the Finance & Audit sub-committee and approved by the Board. The CEO manages the operation of the charity with delegated responsibility to the management team. At its regular meetings, the board is appraised of progress against the operational plan by the executive and receives reports on the current financial position from the Finance & Audit sub-committee. Reports from other sub-committees including the Governance & Nominations sub-committee, Quality & Safety sub-committee, Remuneration sub-committee and newly-established Business Development & Sustainability sub-committee are given as appropriate.

Seven board meetings were held in 2019. Key board activities during the year included:

- At its July meeting, the Board reviewed mid-point progress against the 2017-21 Strategic Plan
- Establishment of a new Business Development & Sustainability sub-committee to advise the board on income generation strategies
- Approval of a new procedure for EI members to make nominations to the Board
- Decisions taken to protect the organisations financial position such as updated financial procedures, reserve designations and bank deposits
- Board member training during the year included sessions on the Governance Code and attendance at the CII Bolder Board training in November
- The President of the International Bureau for Epilepsy accepted an invitation to meet with the Board at its December meeting to discuss international priorities and opportunities to collaborate.

The organisation has achieved the Charities Institute Ireland 'Triple Lock' standard of full 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. The charity will comply in full with the Charity Regulator's Governance Code from 2020.

Epilepsy Ireland has also attained Practical Quality Assurance System for Small Organisations (PQASSO) Quality Mark Level 1 from the National Council for Voluntary Organisations (NCVO) in the UK. PQASSO (Renamed 'Trusted Charity' in 2019) is the leading quality assurance system developed for the non-profit sector, enabling charities to demonstrate standards of excellence in areas such as governance practices, financial and risk management, systems for measuring outcomes and paths to continuous improvement. Epilepsy Ireland achieved this standard in 2015 and it was renewed in 2018.

DIRECTORS' REPORT (CONTINUED)

The Board is satisfied that it meets all legal, compliance and regulatory requirements and that it is equipped with the skills, knowledge and diversity required to meet current and future challenges.

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 by the Board. Risks are analysed under human resources, information technology, fundraising, finance, services, governance, strategic and other. Risks are rated as high, medium or low risks based on the likelihood of occurrence and potential impact.

The Covid-19 pandemic has from March 2020 impacted negatively on all aspects of the charity's activity and has impacted significantly on its risk profile. Many of the organisation's charitable activities (described above) have been suspended and it is uncertain when the organisation will be able to return to normal operations. All face-to-face and group-based support services and training were suspended in March 2020 and these services are being delivered where possible by telephone, email or online. New methods of delivering services online are being developed (e.g. e-learning tools, online support groups) to deal with the likelihood of medium to long term social distancing measures. IT upgrades have been put in place to ensure that staff teams can continue to communicate and collaborate remotely and to mitigate potential HR-related risks.

The Board has increased the frequency of its meetings (remote) since the beginning of the Covid19 emergency with a particular focus on ensuring adequate service delivery, risk management and financial planning. The Board has also delegated authority to the Officers to make decisions on behalf of the board where a full Board decision is not feasible in the circumstances. Contingency plans, budget forecasts and the company risk register are being regularly updated and subject to detailed review. The 2020 Operational Plan is being adjusted and prioritised to reflect the latest public health and financial information available.

The Board anticipates a significant financial implication associated with the crisis. The organisation recognises it is dependent on HSE and other state funding continuing in order to provide its core services. It also recognises that the crisis impacts the ability of the organisation to raise sufficient funds from fundraising activities and earned income to meet current activity requirements and fund the developments envisaged in its Strategic Plan. Public, volunteer-driven or third-party fundraising activities and training income in particular are likely to be severely affected for at least the remainder of 2020. The board has taken a conservative approach in agreeing its projections in relation to its income generating capacity for the next 12 months. These assumptions, along with more general longer-term economic assumptions underpin the board's approach to financial planning and risk management.

However, the board is confident that it will make further decisions as and when required to mitigate the risks and financial impact of Covid-19 through cost reduction and the appropriate use of existing reserves, while continuing to fulfil its mission and charitable objectives in a difficult and uncertain environment. The board is also confident that the organisation's pre-Covid19 financial projections and recent financial performance mean that the organisation is comparatively well positioned to minimise future deficits while continuing to support and represent people with epilepsy and their families throughout the crisis and beyond.

The board is also continuing to monitor the latest guidance, government policy & supports as well as national and international Covid-19 developments. Management is continuing to liaise with voluntary sector representative groups who are working to provide guidance and supports to members to navigate the crisis.

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 2019.

**BRAINWAVE-THE IRISH EPILEPSY ASSOCIATION
T/A EPILEPSY IRELAND**

DIRECTORS' REPORT (CONTINUED)

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	2019	2018
	€	€
Net income for the financial year	7,339	137,562

GOING CONCERN

Since 31 December 2019, the Covid19 pandemic has adversely affected the organisation's operations and created uncertainties regarding its future income-generating capabilities as described within Risks and Uncertainties section. In particular, the Board recognises the organisation's dependence on HSE and other grants in order to deliver its core services.

However, the organisation's forecasts and projections, taking account of the anticipated impact and uncertainties of Covid-19, demonstrate that the Board has a reasonable expectation that the company has adequate resources to operate within the level of its current cash flows and reserves for the foreseeable future.

Thus they continue 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 regarding the adoption of the going concern basis 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:

Mr M. Dowdall (Chairperson to 2 December 2019)
Ms C. Grieve (Chairperson from 2 December 2019)
Mr T. Caravousanos
Mrs T. Dagge
Prof. N. Delanty (resigned 13 May 2019)
Ms M. Fitzsimons
Mr D. Gray
Dr M. Hennessy (resigned 20 August 2019)
Mr A. Kealy
Mr P. Kehoe
Dr B. Lynch (resigned 17 April 2019)
Mr M. McLoughlin (resigned 10 June 2019)
Dr B. McNamara (resigned 10 June 2019)
Ms C. O'Dea
Ms C. Saarsteiner
Major General V. Savino
Dr J. Senior
Dr B. Sweeney (resigned 17 April 2019)

Secretary:

M. C. Grieve (to 2nd December 2019)
Ms C. O'Dea (from 2nd December 2019)

**BRAINWAVE-THE IRISH EPILEPSY ASSOCIATION
T/A EPILEPSY IRELAND**

DIRECTORS' REPORT (CONTINUED)

POST BALANCE SHEET EVENTS

Subsequent to the financial year end Ireland has been impacted by the global Covid 19 pandemic. However, given the unprecedented nature of the outbreak it is not yet possible to determine its full impact on results for the next full financial year.

The Company will continue to monitor the situation and take appropriate measures to adapt to ensure key services continue to be delivered. It is a non-adjusting post balance sheet event.

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

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:

Cathy Grieve
Director

Paul Kehoe
Director

Date: 26th May 2020

**BRAINWAVE-THE IRISH EPILEPSY ASSOCIATION
T/A EPILEPSY IRELAND**

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.

**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 2019 and of its incoming resources and application of resources; including its income and expenditure for the 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

We have nothing to report in respect of the following matters in relation to which ISAs (Ireland) require us to report to you where:

- the directors' use of the going concern basis of accounting in preparation of the financial statements is not appropriate; or
- the directors have not disclosed in the financial statements any identified material uncertainties that may cast significant doubt about the company's ability to continue to adopt the going concern basis of accounting for a period of at least twelve months from the date when the financial statements are authorised for issue.

Other information

The directors are responsible for the other information. The other information comprises the information included in the Reports and Financial Statements for the financial year ended 31 December 2019, other than the financial statements and our auditor's report thereon. 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.

In connection with our audit of the financial statements, 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.

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

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.

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.

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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.

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

02 June 2020

**BRAINWAVE-THE IRISH EPILEPSY ASSOCIATION
T/A EPILEPSY IRELAND**

**STATEMENT OF FINANCIAL ACTIVITIES
(INCORPORATING INCOME AND EXPENDITURE ACCOUNT)
FOR THE FINANCIAL YEAR ENDED 31 DECEMBER 2019**

	Notes	Restricted Funds 2019 €	Unrestricted Funds 2019 €	Total Funds 2019 €	Restricted Funds 2018 €	Unrestricted Funds 2018 €	Total Funds 2018 €
INCOME FROM:							
Donations and Legacies	4	12,500	350,357	362,857	17,970	680,984	698,954
Charitable Activities	5	942,646	188,564	1,131,210	896,298	159,069	1,055,367
Other Trading Activities	6	36,300	195,605	231,905	46,287	201,267	247,554
Investment Income	7	-	2,098	2,098	-	881	881
Other Income	8	-	7,518	7,518	-	43,293	43,293
Total		<u>991,446</u>	<u>744,142</u>	<u>1,735,588</u>	<u>960,555</u>	<u>1,085,494</u>	<u>2,046,049</u>
EXPENDITURE ON:							
Charitable activities	9(a)	1,047,556	351,050	1,398,606	1,077,464	518,902	1,596,366
Raising funds	10	14,520	315,123	329,643	18,515	293,606	312,121
Total		<u>1,062,076</u>	<u>666,173</u>	<u>1,728,249</u>	<u>1,095,979</u>	<u>812,508</u>	<u>1,908,487</u>
Net income/ (expenditure) before taxation		(70,630)	77,969	7,339	(135,424)	272,986	137,562
Taxation	11	-	-	-	-	-	-
Net income/ (expenditure)	13	(70,630)	77,969	7,339	(135,424)	272,986	137,562
Transfers between funds	21	90,687	(90,687)	-	150,975	(150,975)	-
Net movement in funds		20,057	(12,718)	7,339	15,551	122,011	137,562
Total funds brought forward	21	47,107	1,403,572	1,450,679	31,556	1,281,561	1,313,117
Total funds carried forward	21	<u>67,164</u>	<u>1,390,854</u>	<u>1,458,018</u>	<u>47,107</u>	<u>1,403,572</u>	<u>1,450,679</u>

**BRAINWAVE-THE IRISH EPILEPSY ASSOCIATION
T/A EPILEPSY IRELAND**

**BALANCE SHEET
AS AT 31 DECEMBER 2019**

	<i>Notes</i>	2019 €	2018 €
Fixed Assets			
Tangible assets	14	146,383	132,764
Current Assets			
Stock	15	-	10,137
Debtors	16	130,683	101,579
Cash at bank and in hand	17	1,418,723	1,459,045
		<u>1,549,406</u>	<u>1,570,761</u>
Current Liabilities			
Creditors: Amounts falling due within one year	18	(237,771)	(252,846)
Net Current Assets		<u>1,311,635</u>	<u>1,317,915</u>
TOTAL NET ASSETS	22	<u><u>1,458,018</u></u>	<u><u>1,450,679</u></u>
FUNDS OF THE CHARITY:			
Restricted funds	21	67,164	47,107
Unrestricted funds			
- General funds	21	924,900	762,323
- Designated funds	21	465,954	641,249
TOTAL FUNDS		<u><u>1,458,018</u></u>	<u><u>1,450,679</u></u>

The financial statements were approved and authorised for issue by the Board of Directors on 26th of May 2020 and signed on its behalf by:

Cathy Grieve
Director

Paul Kehoe
Director

**BRAINWAVE-THE IRISH EPILEPSY ASSOCIATION
T/A EPILEPSY IRELAND**

**STATEMENT OF CASH FLOWS
FOR THE FINANCIAL YEAR ENDED 31 DECEMBER 2019**

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

	2019	2018
	€	€
Net income/(expenditure) for the year	7,339	137,562
<i>Adjustments for:</i>		
Depreciation	18,304	18,146
Decrease/(increase) in debtors	(29,104)	1,896
(Decrease)/increase in creditors	(15,075)	(102,366)
(Increase) in stock	10,137	(3,712)
Net cash flows from operating activities	<u>(8,399)</u>	<u>51,526</u>
Cash flows from investing activities		
Purchase of tangible assets	(31,923)	(5,699)
Investments Realised	-	-
Net cash provided by investing activities	<u>(31,922)</u>	<u>(5,699)</u>
Change in cash and cash equivalents in the reporting year	<u>(40,322)</u>	<u>45,827</u>
Cash and cash equivalents at the beginning of the reporting year	<u>1,459,045</u>	<u>1,413,218</u>
Cash and cash equivalents at the end of the reporting year	<u>1,418,723</u>	<u>1,459,045</u>
Reconciliation to cash at bank and in hand:		
Cash and cash equivalents at the end of financial year	<u>1,418,723</u>	<u>1,459,045</u>

**BRAINWAVE-THE IRISH EPILEPSY ASSOCIATION
T/A EPILEPSY IRELAND**

**NOTES TO THE FINANCIAL STATEMENTS
FOR THE FINANCIAL YEAR ENDED 31 DECEMBER 2019**

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 11. 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 format 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.

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. Buccal Midazolam (BM) Training Income is recognised when receivable.

1. ACCOUNTING POLICIES (CONTINUED)

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.

Stock

Stocks are valued at the lower of cost and net realisable value.

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.

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.

1. ACCOUNTING POLICIES (CONTINUED)

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.

2. GOING CONCERN

The financial statements have been prepared on the going concern basis. Since 31 December 2019, the Covid19 pandemic has adversely affected the organisation's operations and created uncertainties regarding its future income-generating capabilities as described above in the Director's Report (Risks and Uncertainties section). In particular, the Board recognises the organisation's dependence on HSE and other grants in order to deliver its core services. The HSE has confirmed that it will continue to provide funding under existing service level agreements for 2020

The directors have considered the COVID-19 impact on the company. Given the company's main sources of income were from the HSE and fundraising activities, there was a strong possibility that the company's operation could be affected if its incoming resources were disrupted for a longer period by the pandemic. The company had net current assets of €1.312m (2018: €1.318m), including €1.419m (2018: €1.459m) 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, 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 reviewed the organisation's forecasts and projections, taking account of the anticipated impact and uncertainties of Covid19. The Board consider that the forecasts and projections, together with the reserves held, demonstrate that the Board has a reasonable expectation that the company has adequate resources to operate within the level of its current cash flows and reserves for the foreseeable future (at least twelve months from the date of approval of these financial statements).

Thus they continue 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.

**BRAINWAVE-THE IRISH EPILEPSY ASSOCIATION
T/A EPILEPSY IRELAND**

**NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)
FOR THE FINANCIAL YEAR ENDED 31 DECEMBER 2019**

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.

4. DONATIONS AND LEGACIES

	Restricted funds €	Unrestricted funds €	Total 2019 €	Total 2018 €
Collections	-	158,404	158,404	152,344
Donations	12,500	112,344	124,844	276,050
Memberships	-	25,993	25,993	15,885
Legacies	-	53,616	53,616	254,675
	<u>12,500</u>	<u>350,357</u>	<u>362,857</u>	<u>698,954</u>

5. INCOME FROM CHARITABLE ACTIVITIES

	Restricted funds €	Unrestricted funds €	Total 2019 €	Total 2018 €
HSE funding (service level agreements & National Lottery)	764,273	-	764,273	-
Solas/FAS (Training for Success)	101,814	-	101,814	784,509
Scheme to Support National Org	38,784	-	38,784	90,044
SlainteCare Implementation Fund	32,825	-	32,825	-
Buccal Midazolam (BM) training programme	-	-	-	-
Other grants	4,950	178,939	178,939	149,875
Other income generating services	-	9,625	9,625	21,745
	<u>942,646</u>	<u>188,564</u>	<u>1,131,210</u>	<u>9,194</u>

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**NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)
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6. OTHER TRADING ACTIVITIES

	Restricted funds €	Unrestricted funds €	Total 2019 €	Total 2018 €
Raffles and lotteries	36,300	10,051	46,351	57,157
Campaigns and appeals	-	59,573	59,573	89,900
Fundraising events	-	125,981	125,981	100,497
	<u>36,300</u>	<u>195,605</u>	<u>231,905</u>	<u>247,554</u>

7. INVESTMENT INCOME

	Restricted funds €	Unrestricted funds €	Total 2019 €	Total 2018 €
Interest income	-	2,098	2,098	881
	<u>-</u>	<u>2,098</u>	<u>2,098</u>	<u>881</u>

8. OTHER INCOME

	Restricted funds €	Unrestricted funds €	Total 2019 €	Total 2018 €
Miscellaneous income	-	5,211	5,211	18,197
HSE Reimbursement	-	2,307	2,307	25,096
	<u>-</u>	<u>7,518</u>	<u>7,518</u>	<u>43,293</u>

9(a). EXPENDITURE ON CHARITABLE ACTIVITIES

Activity	Restricted funds €	Unrestricted funds €	Total 2019 €	Total 2018 €
Information and support	533,736	162,568	696,304	828,730
Training and education	296,513	100,060	396,573	389,584
Awareness	98,980	32,068	131,049	177,235
Advocacy	79,092	25,613	104,705	107,635
Research	41,542	28,434	69,975	93,182
	<u>1,049,863</u>	<u>348,743</u>	<u>1,398,606</u>	<u>1,596,366</u>

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9(a). EXPENDITURE ON CHARITABLE ACTIVITIES (Continued)

Activity	Activities Undertaken Directly €	Grant funding of activities €	Support costs (Note 9(b)) €	Total 2019 €	Total 2018 €
Information and support	170,481	-	525,823	696,304	828,730
Training and education	66,975	-	329,598	396,573	389,584
Awareness	6,389	-	124,660	131,049	177,235
Advocacy	1,717	-	102,987	104,075	107,635
Research	4,508	38,725	26,742	69,975	93,182
	<u>250,070</u>	<u>38,725</u>	<u>1,109,810</u>	<u>1,398,606</u>	<u>1,596,366</u>

9(b). ANALYSIS OF SUPPORT COSTS

	2019 €	2018 €	Basis of allocations
Fundraising activities - Staff costs (Note 10)	<u>201,729</u>	<u>195,790</u>	Fundraising from % time spent on activities
Charitable activities			
Charge for financial year			
Staff Costs	945,326	984,738	Utilisation by staff time across 5 activities
Maintenance & Repairs	19,022	9,915	Utilisation by staff time across 5 activities
Office Expenses	64,906	91,513	Utilisation by staff time across 5 activities
Finance & Governance	29,844	74,587	Utilisation of staff time across 5 activities
Depreciation	18,304	18,146	Utilisation by department across 5 activities
(Note 9a)	<u>1,109,810</u>	<u>1,178,899</u>	
Total	<u><u>1,311,539</u></u>	<u><u>1,374,689</u></u>	

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10. EXPENDITURE ON RAISING FUNDS

	Restricted funds €	Unrestricted funds €	Total 2019 €	Total 2018 €
Raising donations, legacies, corporate donations and regular giving	-	63,937	63,937	56,967
Fundraising activities – campaigns appeals and events	14,520	49,457	63,977	59,364
Support costs (Note 9(b))	-	201,729	201,729	195,790
	<u>14,520</u>	<u>315,123</u>	<u>329,643</u>	<u>312,121</u>

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.

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12. EMPLOYEES AND REMUNERATION	2019	2018
Average number of persons employed	27	28
Service delivery	14	14
Fundraising	6	6
Administration	4	5
Training	3	3
	<u>27</u>	<u>28</u>
The staff costs comprise:	€	€
Information & support	351,010	358,797
Training & education	213,262	214,636
Awareness	87,256	94,809
Advocacy	70,742	71,962
Research	18,267	17,926
Administration	145,954	163,369
Fundraising	201,729	195,790
Other compensation costs	5,934	8,243
Redundancy costs	-	-
	<u>1,094,154</u>	<u>1,125,532</u>
Included in the above are costs as follows:		
Employer's PRSI	101,008	102,624
Retirement benefits (note 23)	<u>57,684</u>	<u>57,674</u>

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

	2019	2018
	Number	Number
€60,001 - €70,000	1	0
€70,001 - €80,000	0	0
€80,001 - €90,000	1	1

The total remuneration for key management personnel for the financial year amounted to €193,113 (2018: €179,435). Remuneration included salaries, employer PRSI and pension contributions.

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13. NET INCOME/(EXPENDITURE)	2019	2018
	€	€
The net income/(expenditure) for the financial year is arrived at after charging/(crediting):		
Directors' remuneration and emoluments	-	-
Depreciation	18,304	18,146
Operating lease payments	17,017	18,740
Bank deposit interest	(2,098)	(881)
	<u> </u>	<u> </u>

14. FIXED ASSETS				
	Premises	Fixtures and fittings	Computer and office equipment	Total
	€	€	€	€
Cost:				
At 1 January 2019	122,470	34,051	72,945	229,466
Additions	-	24,403	7,520	31,923
Disposal/write downs	-	-	(8,104)	(8,104)
At 31 December 2019	<u>122,470</u>	<u>58,454</u>	<u>72,361</u>	<u>253,285</u>
Depreciation:				
At 1 January 2019	13,925	31,894	50,883	96,702
Charge for financial year	1,225	5,930	11,149	18,304
Disposal/write downs	-	-	(8,104)	(8,104)
At 31 December 2019	<u>15,150</u>	<u>37,824</u>	<u>53,928</u>	<u>106,902</u>
Net Book Amount: At 31 December 2019	<u>107,320</u>	<u>20,630</u>	<u>18,433</u>	<u>146,383</u>
At 31 December 2018	<u>108,545</u>	<u>2,157</u>	<u>22,062</u>	<u>132,764</u>

15. STOCK	2019	2018
	€	€
Stock of fundraising materials	-	10,137
	<u> </u>	<u> </u>

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

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FOR THE FINANCIAL YEAR ENDED 31 DECEMBER 2019**

16. DEBTORS: Amounts falling due within one year	2019	2018
	€	€
Debtors	72,739	62,754
Prepayments	27,423	18,343
Accrued income	30,521	20,482
	<u>130,683</u>	<u>101,579</u>
	<u><u>130,683</u></u>	<u><u>101,579</u></u>

17. CASH AT BANK AND IN HAND	2019	2018
	€	€
Cash at bank and in hand	1,320,689	1,361,226
Amounts held on behalf of Irish Epilepsy League (note 18)	98,034	97,819
	<u>1,418,723</u>	<u>1,459,045</u>
	<u><u>1,418,723</u></u>	<u><u>1,459,045</u></u>

18. CREDITORS: Amounts falling due within one year	2019	2018
	€	€
Creditors	41,577	89,647
Accruals	29,814	42,095
Deferred income (Note 19)	45,117	-
Amounts held on behalf of Irish Epilepsy League (note 17)	98,034	97,819
PAYE/PRSI/USC	23,230	23,285
	<u>237,771</u>	<u>252,846</u>
	<u><u>237,771</u></u>	<u><u>252,846</u></u>

Epilepsy Ireland holds funds on behalf of Irish Epilepsy League (IEL), the Irish Chapter of the International League Against Epilepsy (the association of healthcare professionals and scientists working in epilepsy). There are no related parties within IEL and it is not under the control of Epilepsy Ireland. Epilepsy Ireland assist IEL in its administration function.

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.

	2019	2018
	€	€
Balance at start of financial year	-	22,250
Amount received in the financial year	45,117	-
Amount released to income in the financial year	-	(22,250)
	<u>45,117</u>	<u>-</u>
Balance at end of financial year (Note 18)	<u><u>45,117</u></u>	<u><u>-</u></u>

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**NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)
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20. FINANCIAL INSTRUMENTS

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

	2019	2018
	€	€
Financial assets		
<i>Measured at undiscounted amounts receivable</i>		
• Debtors (Note 16)	100,162	81,097
	<u> </u>	<u> </u>
Financial liabilities		
<i>Measured at undiscounted amount payable</i>		
• Creditors (Note 18)	41,577	89,647
	<u> </u>	<u> </u>

21. ANALYSIS OF FUNDS

	Opening balance 1 January 2019 €	Incoming resources €	Resources expended €	Transfers €	Closing balance 31 December 2019 €
Restricted funds					
Health Service Executive	21,537	764,273	(857,202)	90,686	19,294
Training for Success	-	101,814	(101,814)	-	-
SSNO	-	38,784	(36,130)	-	2,654
SlainteCare Implementation Fund	-	32,825	(8,309)	-	24,516
Research funding	-	36,300	(36,300)	-	-
Other Grants	25,570	17,450	(22,320)	-	20,700
	<u>47,107</u>	<u>991,446</u>	<u>(1,062,075)</u>	<u>90,686</u>	<u>67,164</u>
Unrestricted funds					
General Funds	762,323	744,142	(613,731)	32,166	924,900
Designated Funds					
- Epilepsy specialist nurses	35,922	-	(33,635)	(2,287)	-
- Premises reserve	220,565	-	-	(120,565)	100,000
- Research provision	150,758	-	(16,945)	100,000	233,813
- Awareness campaigns	34,004	-	(1,862)	-	32,142
- Strategic Plan Implementation	200,000	-	-	(100,000)	100,000
	<u>641,249</u>	<u>-</u>	<u>(52,443)</u>	<u>(122,852)</u>	<u>465,954</u>
TOTAL FUNDS	<u>1,450,679</u>	<u>1,735,588</u>	<u>(1,728,249)</u>	<u>-</u>	<u>1,458,018</u>

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FOR THE FINANCIAL YEAR ENDED 31 DECEMBER 2019**

21. ANALYSIS OF FUNDS (Continued)

HSE-funded services are only partially funded and €90,686 (2018: €150,975) has been transferred from general unrestricted funds to meet the full cost of providing the services.

€19,295 (2018: €21,537) of HSE funds, made up predominantly of National Lottery grants received late in the year are being carried forward for use in 2020 in addition to €20,699 (2018: €25,570) in other restricted grants to be utilised in 2020.

The Board has designated reserves for utilisation in special strategic activities including the funding of a Transition Epilepsy Specialist Nurse position; undertaking epilepsy awareness campaigns; providing funding for current and future research projects and for upgrading/relocating the charity's head office in Crumlin. In addition, the Board maintains a reserve to facilitate implementation of the organisation's Strategic Plan.

Designated funds for the Epilepsy Transition Nurse post were utilised in line with the full cost of providing that service until the conclusion of this post, as planned, in 2019. The remaining balance of €2,287 was transferred to the General Unrestricted Reserve upon completion. The Awareness Campaigns reserve was reduced following expenditure for International Epilepsy Day 2019. The Research Reserve was reduced to cover the costs of research investment not covered by restricted funds.

During the year, the board also agreed to a re-designation of funds as follows:

- €100,000 was transferred from the Strategic Plan Reserve to the Research Reserve to meet future anticipated research funding investments
- The Premises Reserve was reduced to €100,000 in line with the Board's anticipated future requirements. The balance of €120,565 was transferred to the General Unrestricted Reserve to meet future anticipated HSE funding deficits.

As a result of these movements, the General Unrestricted Reserve increased by €162,577 to €924,900 in 2019 and overall designated reserves were reduced by €175,295 to €465,954.

22. ANALYSIS OF NET ASSETS BETWEEN FUNDS

	Restricted Funds €	Unrestricted Funds €	Closing Balance €
Fixed assets	-	146,383	146,383
Current assets	67,164	1,482,242	1,549,406
Liabilities	-	237,771	237,771
	67,164	1,390,856	1,458,018

In respect of prior year

	Restricted Funds €	Unrestricted Funds €	Closing Balance €
Fixed assets	-	132,764	132,764
Current assets	47,107	1,523,654	1,570,761
Liabilities	-	(252,846)	(252,846)
	47,107	1,403,572	1,450,679

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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 €57,684. (2018: €57,674) is charged to the Statement of Financial Activities in the financial year in which it arises. There was €8,970 payable at the financial year-end (2018: €8,558).

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.

25. COMMITMENTS

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

	2019	2018
	€	€
Within one year	24,705	35,000
Between two and five years	-	24,705
	<u>24,705</u>	<u>24,705</u>

Operating lease commitments

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

	2019	2018
	€	€
- Within 1 year	16,680	17,017
- Between one and two years	23,290	27,970
- Between two and five years	-	10,800
	<u>16,680</u>	<u>27,970</u>

26. RELATED PARTY TRANSACTIONS

Ms M. Fitzsimons, a director of Epilepsy Ireland since July 2018, is the Lead Investigator on a two-year research project entitled "Co-producing health and well-being in partnership with patients, families and communities: The role of the epilepsy patient portal" at the Royal College of Surgeons in Ireland (RCSI). Epilepsy Ireland agreed to co-fund this study alongside the Health Research Board (HRB) in the normal course of business in September 2017, nine months before Ms Fitzsimons' election to the board.

During 2019, €10,000 (2018: €10,000) of funding was provided to RCSI, the second and final instalment agreed with RCSI and HRB in 2017. The director does not have a financial beneficial interest in the research, nor did she receive remuneration from Epilepsy Ireland.

27. SUBSEQUENT EVENTS

Subsequent to the financial year end Ireland has been impacted by the global Covid 19 pandemic. However, given the unprecedented nature of the outbreak it is not yet possible to determine its full impact on results for the next full financial year.

The Company will continue to monitor the situation and take appropriate measures to adapt to ensure key services continue to be delivered. It is a non-adjusting post balance sheet event.

There are no other 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.