Annual Report
2016

Prader Willi Syndrome Association Ireland (PWSAI)

Fiscal year ended 31 October 2016

Letter from the Chairman

PWS Association Ireland AGM Meeting June 18th, 2017

The end of another ground break year for PWSAI

Both the PWSAI Main and R&R Subcommittee`s continue to work hard at promoting awareness of PWS and striving to improve the services available to all who live with the condition. It is inspiring to see what a small number of dedicate people can achieve while working together to attain a common goal.

There have been many highlights throughout the year but without a doubt the main event has been the Launch of the National Survey. Everyone on the committee`s working together, with the inputs and engagement of those members who responded to the National survey should be proud of the outcome.

"A Population-Based profile of Prader-Willi Syndrome in Ireland".

This project has taken the best part of 2 years to come from conception to fruition, but will have a lasting benefit for us as an association for years to come. I would like to thank everyone involved especially Prof Louise Gallagher and her research team Sarah-Marie Feighan /Dr Hyun-Ju Kang, Dr Edna Roche, and Dr Marguerite Hughes. It's because of their hard work, commitment, and dedication that this survey became a reality. The work to complete the survey continued through 2016 and into 2017 culminating in the launch officiated at by Minister for Health, Simon Harris, 9th March, Buswells Hotel. The survey presents a significant amount of information and will require, us as a committee, to dedicate time to analyse the results and use them to formulate action plans to progress services for PWS in Ireland, into the future.

Due to the urgent need for PWS specific R&R we as an association have given priority to the R&R Sub-committee to advancing this initiative. The remainder of the main committee are working on information packs for New Born parents/Maternity hospitals, which Emma will give an update on later.

Let's go back and review the year in chronological order.

The Family support Day in Newtown Mount Kennedy last year (14/16th Oct) was a big success thanks to the work put in by Lena Lawlor, Ann Wright, and Families. The activities laid on and the Garda escort went down a treat with young and old. The event continues to grow year on year and its particularly satisfying to see the increasing numbers representing all age groups who are now attending. Can I also acknowledge the sponsorship given by Fields Jewellery, through Paul Wright, to the event, as well as to the Terenure 5 mile run 14 May 2017.

We were delighted that the Minister for Health Simon Harris could meet with the R&R Subcommittee on the Saturday of the family support weekend and give so freely of his time. The Minister listened intently to what we had to say on the day and committed to officiating at the Survey launch on the 9th of March 2017. He then spent time mingling with all those present and facilitated a meet and greet with photo opportunity. Acknowledgement should be given to Jane Cox, who has joined the R&R Sub-committee, as it was through Jane that we as an association got direct contact with the Ministers office.

The preparation for the Survey launch was truly a team effort with a lot of time and commitment given by all into the planning and success of the day. We have been commended by Minister for Health Simon Harris for the Survey and its findings.I`d like to give recognition to those who spoke of their personnel journeys and experiences on the day Ann Jones, Ann O Neill, Rory Tierney, Elisha Doyle(Nolan) and Donnchadh Clancy. It's not easy to stand up and share life stories in such a personnel way. But it was the part of the launch which had the greatest impact on those present. A word of thanks should be given to Caitriona Jones for work put into planning the launch with the event organiser and making the Launch such a success on the day.

It was somewhat disappointing that the launch did not get better coverage on the TV and with National press, although they were present and had recorded interviews. But the event did lead to a segment on Matt Coopers (last word) with Andrea Egan and Elisha Doyle…thanks to them both. Irish Times article with Jane Cox. Limerick FM…. Kerley`s to name but a few.

At the launch, the Minister for Health Simon Harris committed to arranging a meeting between himself, PWSAI R&R subcommittee and the HSE. This he delivered on and the meeting took place on 4th April in Leinster House. This meeting was attended by the Minister, members of his staff, Marion Meany (Head of reform, Disability services in the HSE) and R&R subcommittee. At this meeting PWSAI gave a very comprehensive presentation on PWS, the National survey and particularly the unmet needs of Teenagers and Adults with PWS and the human impact due to lack of PWS Specific Services.

The Minister acknowledged that the Dept. of Health and the HSE did not understand the condition and that the data the survey presented should be used as a valuable source of information to correct this knowledge gap. The Minister directed the HSE to set up a working group with PWSAI and other relevant parties and to use the National Survey as bases for getting a clear understanding on what the unmet needs are for individuals with PWS. The immediate outcome of this working group is to prepare Budget estimates for inclusion in Budget 2018 with the intention that this will be built upon over the coming years. It's frustrating that I should report that as of now this working group has not yet been set up. The Minister has been made aware of this fact. Also the HSE Representative is now Dr Cathal Morgan (Head of operations/ Disability services HSE)

At the same time the R&R Sub-committee has been working with existing and new service providers to highlight the gap in services and the positive momentum gained, through the survey and the meetings with the HSE. PWSAI is prepared to work with any provider who shows interest and competence in providing professional services across as wide a geographical area as possible. The R&R sub-committee arranged a fact finding trip to Denmark. The group that travelled consisted of 4 parents of Adults with PWS and 2 members of Resilience care, who are a service provider keenly interested in learning about PWS and actively working to provide services in the future. (15-18th May). At this stage I`d like to thank Don Tallon for arranging this trip and his ongoing commitment and dedication to advancing the need for PWS Specific R&R services to be made available to all with PWS. I would like to also thank Dr Susanne Blichfeldt for facilitating this trip to Denmark and arranging visits to different PWS Residential services.

It is PWSAI`s intention to have another similar trip to Germany, later in the year, which is in the early stages of planning.

Other media events which helped spread awareness of PWS during the year were:

PWSAI R&R meeting with Minister for Disabilities, Finian McGrath.(15/11/16)

Irish Independent Health and Lifestyle supplement Emma,Rory,Anthony (05/12/16)

Today FM with Alison Curtis(Emma and Rory 14/12/16),

Ireland AM (Rory and Anthony,16/12/16).

The workshops delivered by Ann O Neill continue to be a source of important information and mutual support so for these we thank Ann for her continued commitment. Both Ann O`Neill and Marguerite Hughes, although not members of the committee continue to do important work on behalf of PWSAI.

PWS Fund raising events included:

Lena/Ann fundraising for Family support day

Elaine Murphy,Ann O `Neill and Jane Cox fund raising activities.

Fields Jewellery 06/08/2016

Terenure 5 Mile race 14/05/2017

PWS 5km Maynooth University 18/06/17

If there is anyone I have left out I apologise.

While PWSAI work with the HSE on a higher level it's important that any family whether in need of R&R services in the next few years or not, make themselves known to their CHO Disability Manager. To inform people how to go about doing this there is a R&R Information meeting immediately after the AGM. It is particularly important for those who have signalled a need for R&R services over the next 4 years, but the meeting is open to all who wish to attend. The more families who stress the need for services now and into the future the better chance that this information will be feed up to the decision makers in the HSE.

On a separate note on behalf of PWSAI ,I would like to pass on the best wishes of the committee to Ann Grassick and wish her a speedy recovery from her illness. Our thoughts are with Conor and Colm Grassick also and we hope that suitable services can be arranged following Ann`s heart wrenching story on the Joe Duffy Show.

Finally nothing can be achieved without the hard work and commitment from the Committee members and for that, on behalf of all whom we support, I thank you.

I use this opportunity to encourage anyone who feels they would like to get involved and contribute to the work of the committee to do so by contacting a committee member. This does not necessitate travel for attending meetings as a significant amount of work can be done via e-mail or skype, etc.

I wish all the Fathers present a Happy Fathers Day and hope everyone taking part in the 5Km enjoy themselves.

Regards,

Anthony Carr

Chairman PWSAI

The PWSAI Vision

A world where persons with Prader WIlli Syndrome (PWS), their families, and their carers are supported in all aspects of care, education, and well-being.

The PWSAI Mission

To raise awareness and understanding of PWS and to improve the choice and quality of care, education and support for persons with PWS.

The Origins of PWSAI

PWS was first described in 1956. Just over a quarter of a century later the first child was diagnosed with PWS in Ireland. The Prader-Willi Syndrome Association Ireland (PWSAI) was established in the late 1980s by a small number of parents whose children had been diagnosed with PWS. In 2002 PWSAI became a company limited by guarantee. In 2013 PWSAI amended its governing documents to enable it to start formally registering members.

PWSAI Today

PWSAI is structured as a company limited by guarantee and is run by a board of directors comprising parents of people who have PWS. PWSAI has no paid staff.

The following served as PWSAI directors during 2016:

- Anthony Carr (Chair)
- Sean Kelly (Treasurer)
- Emma Walsh (Secretary) (Appointed 29/6/16)
- Caitriona Dunne
- Lena Lawlor
- Rory Tierney
- Derek Corrigan (Appointed 29/6/16)
- Elaine Murphy (Appointed 29/6/16)
- Ann O’Neill (Resigned 29/6/16)
- Marguerite Hughes (Resigned 29/6/16)

In addition to the directors, PWSAI was assisted by many other volunteers who provided administrative support, organised events, coordinated advocacy efforts, and fundraised. Particular thanks is owed to Don Tallon, Paul Wright, Donnchadh Clancy, Jane Cox and Emer Lane.

PWS 5K 2016

PWSAI's Work During 2016

- We offered one-to-one support and advice by telephone, Facebook and email.
- We disseminated relevant information by means of our website, newsletters, Facebook and Twitter. By the end of 2016 PWSAI had over **542** followers on Twitter and **1,376** followers on Facebook.
- An information meeting on Respite and Residential was hosted by PWSAI in early 2016.
- The PWSAI Family Weekend was a fantastic weekend. in 2016 it was organised by Ann Wright, Lena Lawlor and their families. It had a brilliant turn out, with over 40 families attending.
- The R&R subcommittee met with Minister Simon Harris to discuss the needs of people with PWS with emphasis on respite and residential services.
- In 2016, work continued on the PWSAI National Survey. An incredible 61 families took part and the survey data was collated by the team in Trinity along with support from Marguerite Hughes.
- An article in the Independent in November 2016 with the Tierney family, Anthony Carr and Prof. Roche resulted in a radio piece on Todayfm and an interview on Ireland AM.
- PWSAI continued to do the work necessary to meet its legal requirements including reporting to the Companies Registration Office and the Charities Regulatory Authority.

Plans for the Future

2017 and beyond

During 2017 PWSAI will continue to work on the ongoing projects that received funding from the Galway Cycle as well as other projects that have been identified as necessary by PWSAI's committee and members. A sub committee has been formed and the New Diagnosis information pack will be released in 2017.

PWSAI will continue to work on creating additional resources for families and professionals working with people with PWS.
PWSAI will continue to provide opportunities for people with PWS and their families to meet and learn from one another.

PWSAI remains acutely aware of the need to provide additional supports to teenagers and adults and the pressing need for respite and residential services. PWSAI's residential and respite subcommittee will continue to work in this area.

All of PWSAI's work relies on the willingness of suitably qualified volunteers to give of their time.

Fundraising & Awareness Spreading

2016 was another good year for PWSAI. The Hospital Saturday Fund generously donated €2,700 to PWSAI in support of its family weekend. In addition, many PWSAI members organised or participated in events to raise money for PWSAI. Particular thanks to Edel and Jayne Harrison, Oisin and Ann O'Neill, Jane and Laura Cox, Elaine Murphy and the Wright and Lawlor families for their fantastic fundraising during 2016. A special mention to Fields who not only raised funds for PWSAI but helped spread awareness of PWS. Many other members made personal donations to PWSAI.

The third PWS 5km, organised by Emma Walsh and Rory Tierney, was also a huge success with €4500 raised. Thanks to everyone who supported the PWS 5K.

PWSAI is very grateful to all the individuals and organisations who donated money, participated in or organised fundraisers, or raised awareness of PWS during 2016.

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Irish Independent Health and Lifestyle supplement Emma,Rory,Anthony (05/12/16)

Today FM with Alison Curtis(Emma and Rory 14/12/16),

Ireland AM (Rory and Anthony,16/12/16)

Marl Wright & Peter Lawlor fundraising 2016

PWS 5K 2016

Fields Fundraiser 2016

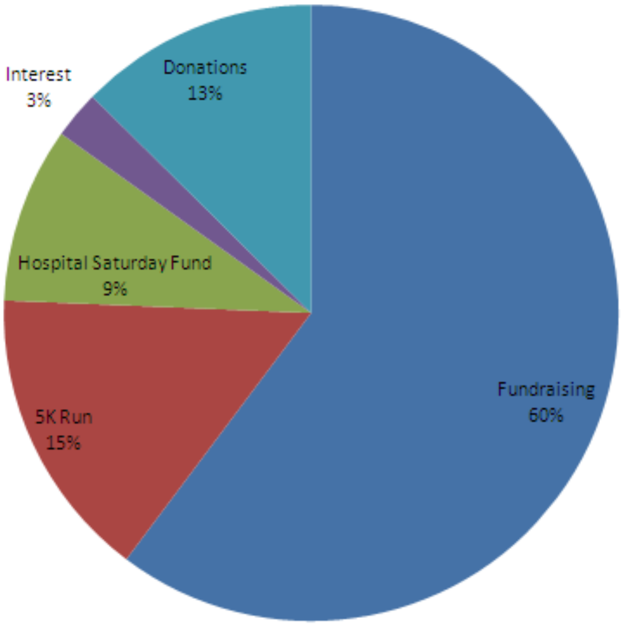
2016 Treasurer’s Report

Income for the year ended 31st October 2016 was €29,189 compared to €16,367 for the previous year. 2016 was a fantastic year for PWSAI in terms of fundraising with over €17,500 raised. On behalf of the association I would like to thank everyone involved in this amazing effort. In particular I would like to thank Paul Wright and all the people at Fields who raised over €5000.

The annual 5K run is going from strength to strength and raised €4,500 this year so well done to everyone involved and thank you to Rory and Emma for their continued efforts in making this such an enjoyable event for all the family.

Once again the family day was a huge success. Lena & Ann organised a brilliant weekend which was enjoyed by everyone. The cost of the family weekend was fully funded by the fantastic fundraising efforts of Lena, Ann and their team. A huge thanks to you both.

2016 Treasurer’s Report Income



Fundraising	€17,575
5K Run	€4,496
H. Sat. Fund	€2,700
Interest	€733
Donations	€ 3,670
Total	**€29,189**

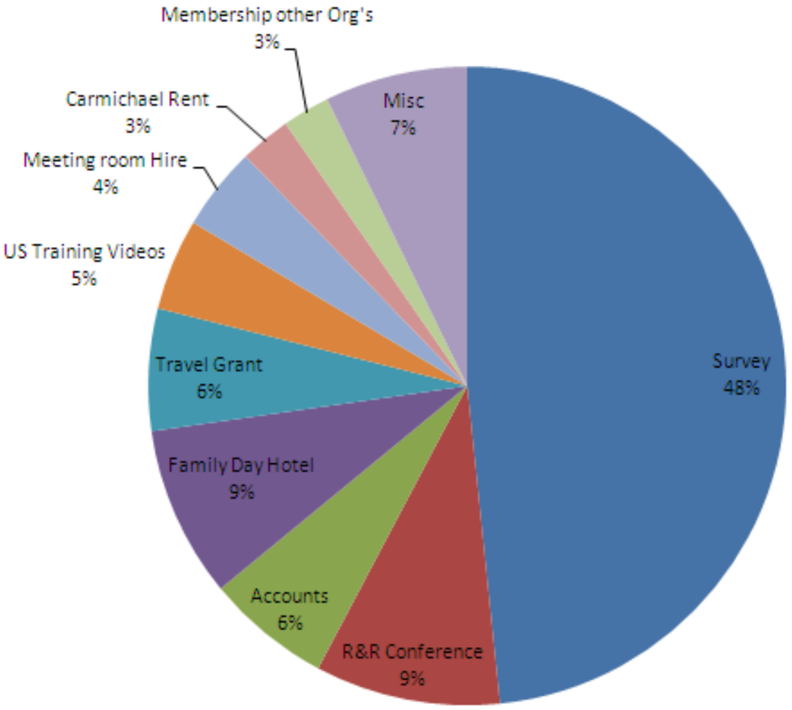
2016 Treasurer's Report Expenditure

Expenditure

Expenditure in 2016 was €24,934. 50% of this total was spent on The National Survey.

Income & Expenditure 2016

Income	€29,189.	Expenditure	€24,934



Survey	€12,058
R&R Conference	€2,339
Family Day Hote	€2,163
Accountant Fees	€1,577
US Videos	€1,156
Travel Grant	€ 1,540
Rent	€ 644
Meeting Room	€ 1051
Membership of Org's	€ 601
Miscellaneous	€1,805
Total	**€24,934**

Miscellaneous Expenditure	
Phone	450
Legal Fees	308
Bank Fees	107
Insurance	254
Printing	86
Balloons (5K)	279
Workshop	150
Expenses	170
Total	**1804**

Family Weekend 2016

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