



INTERNATIONAL ALLIANCE OF ALS/MND ASSOCIATIONS

24th Annual Meeting
Sunday and Monday, 4-5 December 2016
Liffey Hall 2, Convention Centre Dublin

AGENDA

SUNDAY, 4 DECEMBER 2016

- 08:45 1 Welcome & Introduction (30 min)
- 09:15 **Annual General Meeting** (45 min)
- 10:00 2 Opening Remarks from the General Manager (15 min)
- 10:15 **Morning Refreshments** (30 min)
- 10:45 3 Welcoming Our New Members (15 min)
- 11:00 **Programming for PALS/CALS** (60 min)
- 4 *Beyond Awareness Gaps*
 Hiroki Okabe, Japan ALS Association
- 5 *The Cost of Achieving Your Goals: Assistive Technology Program in Israel*
 Efrat Carmi, IsrALS
- 6 *A Comprehensive Information and Education Resource for People with MND, their Carers, Health and Community Care Providers*
 Gina Svolos, MND Australia
- 7 *New Challenges to Our Association*
 Alessandra Dorca, ALS Pro-Cura Association
- 12:00 **Lunch** (60 min)
- 13:00 **Programming for PALS/CALS Continued** (30 min)
- 8 *ACELA: A Vision of Hope*
 Rocio Reyes, ACELA, Colombia
- 9 *Life Is Now*
 Gudjon Sigurdsson, MND Iceland
- 13:30 **Partnerships and Collaborations** (90 min)
- 10 *A Phased Shift in MND Care in Scotland*

Craig Stockton, MND Scotland

11 *Victories and Partnerships*
Tatiana Mesquita e Silva, ABrELA

12 *Local Fundraising for Project MinE*
Gorrit-Jan Blonk, ALS Netherlands

13 *Using the MND Association's Experience to Promote Optimal Care and Support in Russia*
Anna Kassianova, Martha-Mary Medical Centre "Miloserdie"

14 *The South African MND Caregiving Experience: Lessons Learned from a Cross-Country Collaboration*
Melinda Kavanaugh, University of Wisconsin-Milwaukee

15 *First Ever ALS Student Exchange*
Jodi O'Donnell, Hope Loves Company

15:00 **Refreshments** (30 min)

15:30 **Research and Science** (60 min)

16 *The ALS Analyzer Mobile App: Engaging PALS in the Development of New ALS Monitoring Tools*
Idit Ron, Prize4Life

17 *PULSE*
Christine Tabuenca, ARSLA

18 *Precision Medicine: How Can It Help Advance the Discovery of ALS Subtypes and Speed Drug Development?*
Rob Goldstein, ALS Therapy Development Institute

19 *Meeting the Research Communication Challenge: Our Experience*
Sally Light, MND Association of England, Wales and N Ireland

16:30 **Networking** (30 min)

18:30 **"Warm & Fuzzy" Dinner**

MONDAY, 5 DECEMBER 2016

09:00 20 Update on the Strategic Plan: 2016-2019 (30 min)

09:30 21 Workshop (60 min)

10:30 **Morning Refreshments** (30 min)

11:00 **Scientific Update** (30 min)

22 *Scientific Update*

Dr. David Taylor, ALS Canada

11:30 **ALS Investment Fund** (15 min)

23 *ALS Investment Fund*

Gorrit-Jan Blonk, ALS Foundation of the Netherlands

11:45 **Good Governance** (15 min)

24 *Keys to Strong, Transparent Governance*

Andrea Pauls Backman, Les Turner ALS Foundation

12:00 **Invitation to Boston 2017** (10 min)

ALS TDI, ALS Hope Foundation

12:10 ***Thank You & Close: Meeting Adjourns (Group Photo)***

12:30 Lunch (60 min)

14:30 **"Ask the Experts"**

19:00 Dinner hosted by the IMNDA

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Alliance Meeting Programme Committee

Efrat Carmi, IsrALS, Israel

Sara Feldman, The ALS Hope Foundation, USA

Dr. Alper Kaya, ALS-MNH Dernegi, Turkey

Tammy Moore, ALS Canada

Speaker:

Hiroki Okabe

Member Association:

JALSA

Title of Presentation:

Beyond Awareness Gaps

Theme:

Programming for PALS/CALS

Abstract:

We describe how PALS and their families developed a round-the-clock in-home caregiving system by utilizing public funding and training personal assistants (PAs).

In the late 1990s, PALS and their families in Tokyo began to train PAs, an approach that was described as the "SAKURA MODEL" at the APF in 2006.

In 2016, many PALS in Japan successfully use PAs who perform tracheotomy suctioning, tube-feeding, and other forms of assistance.

We created a 180-second film to raise awareness of ALS. It features Hiroki Okabe who is living with ALS. It tells the story of an ALS patient who is using PAs and enjoying his daily life.

Our PA training program has solved many problems, such as the lack of caregivers and the provision of care by caregivers lacking the necessary skills.

By educating and training personal assistants themselves, PALS are able to enjoy the benefits of proper and efficient care. This approach in which patients take charge of their own care can transcend cultural and political differences and be employed throughout the world. A re-examination of how we think about costs and benefits when it comes to patients with incurable illnesses is also needed.

Speaker:
Efrat Carmi

Member Association:
IsrALS

Title of Presentation:
The Cost of Achieving Your Goals: Assistive Technology Program in Israel

Theme:
Programming for PALS/CALS

Abstract:
IsrALS is working hard that all ALS patients in Israel will be able to communicate. For 5 years we have been running an assistive technology program: 4 Occupational Therapists are traveling through the country and making home visits to evaluate and assess patients' abilities and recommend the right technology for the identified needs. A team of volunteers continues the process and helps patients adjust and implement the technology systems.

Last year, after a long fight, IsrALS has succeeded to convince the government to include all the technology equipment expenditures in the benefit package that ALS patients get from the state. The immediate result was a significant increase in the demand for our service and a sharp increase in our program costs. On one hand we are getting closer to achieving the goal of all ALS patients using Assistive Technology but on the other hand as an organization we need to find funding for the expanding program.

Speaker:
Gina Svolos

Member Association:
MND Australia

Title of Presentation:
A Comprehensive Information and Education Resource Service for People with MND, Their Carers, Health and Community Care Providers

Theme:
Programming for PALS/CALS

Abstract:
This paper will describe the current information and education resources that the Motor Neurone Disease Association of NSW provides and describe their development. Programs include face to face education programs and online training as well as a range of publications to assist people with MND, their carers and service providers to understand MND and provide the best possible care.

Education programs include: Information Evenings for newly diagnosed; Living Well with MND – an information day about living well with MND for people with MND, their family and friends; MND Aware - a face to face and online training program for health and community care providers; Carer Education Programs- 4 days in metropolitan areas and a 2 day residential in regional areas.

Publications complement the education programs and have now been organised into two series. The Aspects of Care Series for health, community and residential aged care facilities and the Living with MND series designed for people living with MND and their families.

These comprehensive information and educational resources value add to the work of the MND Advisors and the MND NSW Information Line.

Speaker:

Alessandra Dorça

Member Association:

ALS Pro-Cura Association

Title of Presentation:

New Challenges to Our Association

Theme:

Programming for PALS/CALS

Abstract:

Pro-Cure ALS was established in 06/26/2013 in order to assist patients with Motor Neuron Disease Association (MND) / Amyotrophic Lateral Sclerosis (ALS) and direct caregivers and family members who need support throughout Brazil, a country with critical levels of management in health services. Pro-Cure ALS Association's mission is to provide education, information and support care for patients across the country. It was established when people involved directly or indirectly with the disease teamed up to improve the quality of life of these patients.

Pro-Cure ALS Association raised US \$ 265,000.00 with the Ice Bucket Challenge in 2013, which allowed us to address various needs of patients, such as ventilatory support, diets, assistive communication devices and a lot of assistance with information and training for caregivers and family members. Equipment was made available to needy patients until we achieved justice and the law determined that the government should provide the equipment to the patient. Thus, the Association was able to help a greater number of patients, especially those who do not have access to the equipment due to their socio-economic condition.

Since its inception, the Association has released 46 BIPAPS Respiration Synchrony II, 150 resuscitation bags, 9 assisted communication devices PC EYE GO Tobii, 9 Fans Trilogy Respiration Philips, 9 Cough Assists, plus air mattresses and many other items such as food supplements and diapers.

The Association also held caregivers' assisting courses, symposiums for education, training and professional education and conducted several visits to patients.

The power of social media was tapped to reach patients in remote parts of Brazil. The Association group has more than 12,400 members on Facebook, 5,000 registered, and of these, approximately 35% are patients. The officers and directors of the Association constituted a cohesive group which remains online daily, reaching even distant patients, meeting many of their needs.

After the Ice Bucket Challenge, the Association began to have difficulty in raising funds, and in order to improve this situation, it was necessary to find strategies to solicit donations. We conducted online campaigns to coincide with the anniversary of the organization and sent donation requests. Nationally-recognized actors engaged in the global campaigns of the Alliance, and annually in August in the Ice Bucket Challenge.

Pro-Healing Association of ALS still encounters obstacles every day, but the group of officers, directors and its members have worked to put this issue in the national media, because this way, more partners will join the cause.

Speaker:

Rocio Reyes

Member Association:

ACELA

Title of Presentation:

ACELA: A Vision of Hope

Theme:

Programming for PALS/CALS

Abstract:

ACELA (Asociación Colombiana de Esclerosis Lateral Amiotrófica) is a non-profit association dedicated to promote the quality of life and well-being of people with ALS and their families.

ACELA is a Colombian organization comprising around 120 individual members. Its key roles include providing assistance and information to build hope, spread a positive attitude and enhance quality of life of people with ALS and their families.

The five main volunteers, who are the driving force behind the association are facing (or have faced) this disease within their own families and, through their living experiences, they had identified two (2) main needs for the people with ALS:

- 1) Uncertainty and fear of how to live with a continuous increment of physical limitations.
- 2) 2) Lack of information of how to change their daily living to seek a well-being in every stage of the ALS.

ACELA's mission is achieved through phone assistance, individual face-to-face meetings, home visits, workshops/group meetings and strategic alliances with educational and health entities in the country.

This association seeks to empower people with ALS and their families to live fuller lives by accepting their disease with courage and hope.

Speaker:

Gudjon Sigurdsson and Arny Gudjonsdottir

Member Association:

MND Iceland

Title of Presentation:

Life is Now

Theme:

Programming for PALS/CALS

Abstract:

We will tell you about the MND Association of Iceland's work in 2016 for PALS and carers. We have an apartment for our members to use, to avoid hospital living. We took members on a trip to Denmark, and also helped our members relax and enjoy life for a few days at a hotel in Southern Iceland. Now, we are getting ready to welcome kids from the USA in cooperation with HLC and their program in 2017. This is to make the point that we shall never forget that life is now, not later for most of us.

Speaker:

Craig Stockton

Member Association:

MND Scotland

Title of Presentation:

A Phased Shift in MND Care

Theme:

Partnerships and Collaborations

Abstract:

The last few years have seen the 'coming together' of various elements essential to improving the care of people with MND within Scotland. Working with the Scottish Government, the National Health Service, Universities/Researchers, MND Scotland and people affected by MND, the foundations are in place that will allow there to be significant improvement in MND patient care over the coming years. An integrated strategic approach involving political engagement, national oversight and coordination of the MND Care Services and the establishment of an MND care-research infrastructure has created the environment in which MND care within Scotland can move forward. Key elements such as the standardisation of data collection, doubling of MND Nurses and changes to legislation have started the process. This presentation will highlight how some of the elements have come about and the challenges and opportunities that they bring.

Speaker:

Tatiana Mesquita Silva

Member Association:

ABRELA

Title of Presentation:

Victories and Partnerships

Theme:

Partnerships and Collaborations

Abstract:

The Brazilian Association of Amyotrophic Lateral Sclerosis (ABRELA) was established in 1998. Since then, ABRELA is attentive to the main needs of ALS patients, achieving several victories:

- We provide information through periodic meetings for patients, families and caregivers and the website: www.abrela.org.br.
- People with ALS in Brazil now have the right to receive special medicines free of charge through Federal Ordinance
- People with ALS in Brazil now have the right to receive a non-invasive home ventilator (BiPAP) through municipal health departments

For our survival, beyond financial donations, ABRELA forms partnerships with several objectives:

- 1) Disclosure and guidance
- 2) Customer patient
- 3) Fundraising
- 4) Institutional Partnerships

Here are some of the organizations and institutions ABRELA has developed partnerships with:

- The Multidisciplinary ALS Clinic of Neuromuscular Diseases Section of UNIFESP / EPM / HSP
- Specialized Physical Therapy Intervention in Neuromuscular Diseases - www.latoneuro.com.br
- The Brazilian Academy of Neurology - Scientific Department of Motor Neurone Diseases - www.abneuro.org.br
- IMG Content, a production company made up of filmmakers, advertisers, TV professionals, journalists and designers to find the best ways to create effective communication and results - www.imgcontent.com.br
- Instituto Paulo Gontijo - www.ipg.org.br

We also partner with Mrs. Mara Gabrielli, a politician. Even though the association is non-political, we need some political help in advocating for the needs of patients to the government. Whenever there is a problem to be solved with the government, Mrs Mara assists in scheduling meetings and participates in them. This helps us raise awareness of ALS and get the needs of PALS addressed.

Senator Romario Farias also helped us to perform the Brazilian Symposium on ALS in Brasilia this year. This event was held in partnership with the MOVELA association - Movement in Defense of the Rights of the person with ALS; ABLE - Brazilian Association Fighting Against ALS, and Afaf - Association of Family, Friends and Graves Disease Carriers.

Speaker:

Gorrit-Jan Blonk

Member Association:

ALS Netherlands

Title of Presentation:

Local Fundraising for Project MinE: Challenges and Strategies for Success

Theme:

Partnerships and Collaborations

Abstract:

Project MinE is the largest, international, groundbreaking research project dedicated to systematically investigating the human genome for both common and rare genetic variations of ALS. To support analytical goals, the project aims to collect and sequence DNA samples of 15,000 ALS patients and 7,500 control subjects, a total of 22,500 DNA profiles.

Founded in 2013 by three Dutch ALS patients and entrepreneurs, Bernard Muller, Robbert Jan Stuit and Garnt van Soest, the project started off with three countries: The Netherlands (coordinating), Ireland and Belgium. Within a year, the consortium expanded with 9 more countries. As of today, 16 countries are partnering, each having set their own goal of samples to contribute to the grand total.

Collaboration within a country is key for participating in Project MinE. The principal investigators of ALS research center(s) partner with a national ALS foundation to join Project MinE. The ALS research centre assures the availability of samples (and clinical core data), and the ALS foundation commits to raise the funding for sequencing of these samples.

Crowd funding for Project MinE is a big challenge, but is crucial for the overall success of the project. The ALS Netherlands and the ALS Liga (Belgium) have been very successful in raising funds for a high number of samples in a short period of time. Big events like the Amsterdam City Swim have been very helpful. Also, the USA, Spain and Ireland, among others, are well on their way to reach their fundraising goals. Other foundations joined recently and prepare funding strategies or anticipate challenges in organisational structures and fundraising policies.

Sharing the story of those foundations who were able to achieve to their funding goal, will hopefully help other foundations to set or adjust their strategies for successful fundraising and contribute to the local and international success of Project MinE!

Speaker:

Anna Kassianova

Member Association:

Martha-Mary Medical Center "Miloserdie"

Title of Presentation:

Using the MND Association's Experience to Promote Optimal Care and Support for People Living with ALS/MND in Russia

Theme:

Partnerships and Collaborations

Abstract:

The MND Association of England, Wales and N Ireland invited people from the Russian ALS Foundation "Live Now" and Martha-Mary Medical Center "Miloserdie" to visit the MND Association office in Northampton to share experiences.

During our visit, we got a comprehensive view of the MND Association's activities: raising awareness, fundraising, providing information, improving care and supporting research. We discussed the structure of MND Association and strategies to reach every family affected by ALS and provide equal support to them.

Keeping in mind the MND Association experience, on 22 of August 2016, we opened our first branch in Saint Petersburg, a city with 5 million inhabitants. Thus, our communication with colleagues from MND Association is of great help in setting the framework we will use to promote care and support for people with ALS/MND in Russia.

Speaker:

Melinda Kavanaugh

Member Association:

University of Wisconsin – Milwaukee (cooperating with MNDA South Africa)

Title of Presentation:

The South African MND Caregiving Experience: Lessons Learned from a Cross-Country Collaboration Between the US and South Africa

Theme:

Partnerships and Collaborations

Abstract:

Funded by an Alliance Support Grant for Partnership through the Alliance, this cross-country project was developed as an exchange of knowledge between MND families, care staff in South Africa and collaborators conducting similar interviews in the US. The project sought to assess previously unknown information and detail about the South African experience in order to inform the development of support programs and education for MND families and youth in South Africa. The ALS Association in the US is currently developing national youth and family programs. However, whether these same types of programs would be useful, culturally appropriate, or accessible to isolated families in South Africa is unknown.

Program description

Using data from US caregiving programs to guide family meetings, collaborators from the US travelled to South Africa to engage with the MND Association of SA and clinics in Johannesburg and Cape Town. All families with MND, and who had a child/youth 18 and under in the home were asked to participate in interviews and meetings with the US team and clinic staff. A total of 20 families in both Cape Town and Johannesburg participated.

Meeting outcomes

Both adults and youth stated a clear need for more assistance from the association and others. However, access to and engagement with the association greatly varied by location and access to the few care coordinators available. Families detailed the need for support, equipment, transportation assistance and financial help. Across locations, youth engage in numerous and intense caregiving tasks. They felt a strong sense of responsibility for care, even when it impacted school and their own well-being. Patients recognize the intensity of care provided by youth, yet had no other choice due to isolation, financial limitations and few supports. Both parents and youths described the need for in-person supports, and educational programming.

Implications and next steps

Neither the medical clinics nor the MNDA had conducted any assessment of patient, family and youth needs. Thus, this project has both immediate and long term implications for care and support development for families in South Africa and capacity building in clinics and the association serving MND patients. Given the lack of youth caregiving training, intensity of care provision, and minimal education about MND, developing programs will be a crucial aspect to improving QOL in patients and their families – building capacity across clinics and patients. Stellenbosch University School of Social Work in Cape Town will add to the capacity building, by engaging their students to assist in the development of training and support programs for youth caregivers and in-person support.

This project highlights the vital importance of cross cultural information sharing and engagement with families to develop relevant programs for families affected by MND in South Africa, by hearing the voices of these families. Due to limited funds, families in South Africa do not have the luxury of the level of support and care provided in many places, including the US. Therefore, conducting interviews and assessments will help guide the limited funds and inform grants and outside funding to provide the targeted support and care needed for these isolated and vulnerable families.

Speaker:

Jodi O'Donnell Ames, President and Founder; Nancy Yantas, Director of Communications

Member Association:

Hope Loves Company

Title of Presentation:

First Ever ALS Student Exchange

Theme:

Partnerships and Collaborations

Abstract:

Jodi O'Donnell-Ames has been in the ALS trenches since 1995 when her young husband Kevin O'Donnell was diagnosed with the disease at age thirty. Kevin lost his battle with ALS in 2001. After finding no resources for her children as they coped with the loss of a parent to ALS, Jodi founded Hope Loves Company (HLC) in 2012. The mission of Hope Loves Company is to provide emotional and educational support to children and young adults who had or have a loved one battling ALS.

Hope Loves Company has sent hundreds of free books to help families explain ALS to their children. In addition, it sends Hugs of Hope care packages to children caregivers. Jodi speaks to students in schools to inform them about ALS. She also heads up Camp HLC®, a free weekend retreat for children, young adults and their families to connect, make friends and feel supported. To date, there have been 7 camps in four states.

In 2015, at the International ALS/MND Alliance meeting, Mr. Gudjon Sigurdsson expressed interest in bringing HLC children from the U.S. to Iceland. Because of Mr. Sigurdsson's enormous efforts, this exciting event will take place in July, 2017. The mission is threefold:

To encourage international student exploration and relations while having fun.

- To unite young adults from two countries who understand ALS and the impact it has on families.
- To work on a combined project (as a group) that will be used to help other young adults via HLC and MND Association of Iceland.

This program is a direct result of the International Alliance and the work/relationships it fosters.

Mrs. O'Donnell-Ames will share with the International Alliance how other interested countries can get involved in the program.

Speaker:

Idit Ron

Member Association:

Prize4Life

Title of Presentation:

The ALS Analyzer Mobile App – Engaging PALS in the Development of New ALS Monitoring Tools

Theme:

Research and Science

Abstract:

Prize4Life is a non-profit organization dedicated to accelerating the discovery of treatments and a cure for ALS by identifying and removing barriers facing ALS researchers and pharmaceutical companies. One such barrier is the limited data and rudimentary diagnostic tools used to monitor and evaluate ALS disease progression today. The only quantitative measure for disease progression is the ALS functional rating scale questionnaire (ALSFRS-R): a highly subjective tool (both from the perspective of the clinician and the patient), which requires severely immobile patients to attend a clinical visit whose outcomes are logged privately and not stored in any central repository. Thus, not only is ALS research hindered by the poor record of the natural course of disease progression, but patients are often left with inadequate monitoring and clinical care.

Prize4Life has been working to solve this problem by developing an affordable, accessible and accurate tool to track ALS progression - the ALS Mobile Analyzer. This free smartphone-based application monitors patients in their natural environment and collects objective, ongoing, comprehensive daily-life data. The ALS Mobile Analyzer utilizes the clinically approved questionnaire, and collects further data through active tasks and passive phone sensors. We aim to create the largest ALS database ever, containing multi-modal functional data that will be freely accessible to researchers. This one of its kind large scale central repository of detailed digital measurements will enable the development of easy to use objective tools to assess, quantify and understand ALS disease progression, thereby bringing us closer towards finding a cure.

As an organization founded and managed by ALS patients, Prize4Life's long held belief is that ALS patients can and should take an active part in the fight against the disease. The ALS Mobile Analyzer app is a unique opportunity to engage and empower all patients from around the world to take part in a project that will help change the face of ALS research and shorten the path to finding a cure.

Speaker:

Christine Tabuenca

Member Association:

ARSLA

Title of Presentation:

PULSE

Theme:

Research and Science

Abstract:

One of principal missions of ARSLA is to support the ALS research in France. In 2014, ARSLA collaborated with the Lille's Hospital for a new research protocol "PULSE": prognostic value of biomarkers in ALS. ARSLA finances this research program at the level of 1.5 million Euros. ARSLA is co-owner of the data.

Amyotrophic lateral sclerosis is not a single disease; in fact, it is a spectrum of diseases with very different etiological and physiopathological mechanisms. Decades of treatment failure should prompt a change in the research strategy in ALS. It is essential to characterize subgroups of patients and monitor their disease progression profiles in order to assign prognostic value to parameters recorded at the time of diagnosis that may facilitate inclusion in dedicated clinical trials.

We therefore consider that it is essential to set up a multidisciplinary study of a very large number (n=1000) of ALS patients with prospective, collaborative monitoring by all the French ALS centres – from the initial signs of disease through to death. This approach would provide the necessary statistical power to define the predictive factors of the different pathological patterns that may help recruitment in future clinical trials.

No one has ever analyzed the full set of clinical, biological, genetic, radiological, histological and electrophysiological data in a large number of ALS patients. Most research provides isolated genetic studies that are not able to address the various prognostic factors and endophenotypes of ALS.

PULSE could establish precise prognostic criteria and identify harmful disease progression mechanisms and predictive factors in order to better select patients for future therapeutic trials. PULSE could also provide an opportunity to check preclinical scientific hypotheses in patients (since the current preclinical models have low predictive value) and thus guide new therapeutic strategies.

PULSE will help to harmonize, reinforce and promote the French ALS network and the latter's European and worldwide collaborations. In fact, PULSE has already started to perform training and to harmonize assessments in France. PULSE is already associated with the European projects led by Professor Van Den Berg (SOPHIA, NEUROMOTOR, and MINE).

Speaker:

Robert Goldstein

Member Association:

ALS Therapy Development Institute

Title of Presentation:

Precision Medicine: How Can it Help Advance the Discovery of ALS Subtypes and Speed Drug Development?

Theme:

Research and Science

Abstract:

In 2014, the ALS Ice Bucket Challenge occurred and we were humbled recipients of direct donations from individuals totaling USD\$3.5 million. This allowed us to expand and accelerate our first of its kind Precision Medicine Program in ALS from 20 people to 300. The Precision Medicine Program came out of the globally accepted need to identify the various subgroups of ALS for targeted drug development using patient (iPSc) derived cell lines as an initial screening tool. Because of our unique marketing and community development approach, we were able to fully enroll this 300-person research study in less than 24 months with participants from 40+ US states and 9 different countries. This was a quicker and more diverse enrollment cohort than any other similarly designed research study in ALS with only a single enrollment center. In addition, we shared all the data produced in the study, including genetic data, movement and progression data and cell line creation work with all those enrolled in the program. This too had never been done before in any similar program utilizing online reporting systems. This presentation will provide insights into how we were able to rapidly enroll this research study, overcome barriers with sharing potentially sensitive information with participants online, incentivize participants to add data consistently over the last 24+ months and generally break ground by applying precision medicine techniques in ALS. Many others are now also building on these initial efforts. In addition we aim to share information about how other ALS organizations can think about funding similar projects or partner with the ALS Therapy Development Institute to expand the Precision Medicine Program concept into their own countries. This presentation will not require deep science knowledge to understand.

Speaker:
Sally Light

Member Association:
MND Association (England, Wales and Northern Ireland)

Title of Presentation:
Meeting the Research Communication Challenge: Our Experience

Theme:
Research and Science

Abstract:

Research is the first of three mission areas for the MND Association. People with MND and our wider membership tell us it is their priority. When we asked them what we should spend our IBC money on 80% said research. We also know that participating in research studies is something many pwMND are keen to do. This means we have a big responsibility to communicate our research work to them. This presentation will share with Alliance members some of the ways that we do that - identifying our various audiences, the variety of ways in which we try to communicate and also touch on some of the challenges. We currently have £13m invested in research projects across a wide range of areas from small health care projects to international gene hunting. We have three main communication audiences - pwMND and their families, our wider membership which also includes our volunteers and health and social care professionals, and our research community. We use a wide range of social media, digital and more traditional channels of communication and responsibility sits largely with three members of staff out of a research team of eight. In communicating the challenges I will discuss the attention of animal rights activists that we have received, and our response to that, and also the challenge of coping with the increasing demand for bespoke answers to questions from our members. As part of the presentation I will provide examples for Alliance members to take away or access and I hope that our experience will be of value to others in their own work.

Speaker:

Gorrit-Jan Blonk

Member Association:

ALS Netherlands

Title of Presentation:

ALS Investment Fund

Theme:

Research and Science

Abstract:

Gorrit-Jan Blonk will present on the ALS Investment Fund concept. The fund is an investment model meant to create new opportunities to fundraise for ALS research and help speed up the process of discovering drugs and bringing them to market.

Speaker:

Andrea Pauls Backman

Member Association:

Les Turner ALS Foundation

Title of Presentation:

The Keys to Strong, Transparent Governance

Theme:

Good Governance

Abstract:

In order to inspire confidence in: (a) people with ALS and their families who need assistance; (b) researchers and clinicians who choose to be affiliated with the organization; and (c) donors who want to know that their gift is providing meaningful impact, the key is strong, transparent governance. The Les Turner ALS Foundation has established structures to provide such confidence, including a strong advisory council and external advisory board of leading ALS experts that review research and clinical grant applications, internal board committees overseeing the areas of finance, governance, patient services and development, and strong financial stewardship. In 2015, the Foundation allocated a very high 88 cents of every dollar to its mission: funding of ALS research and clinical care as well as providing direct support services and education. Resource allocation both at the research grant level and the patient grant level is administered by a clear set of guidelines and open communication. This presentation will briefly show the evolution of these structures to their current-day status and will show the benefits of transparency in governance.



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