



#1 VOICE SUMMIT MEETING REPORT

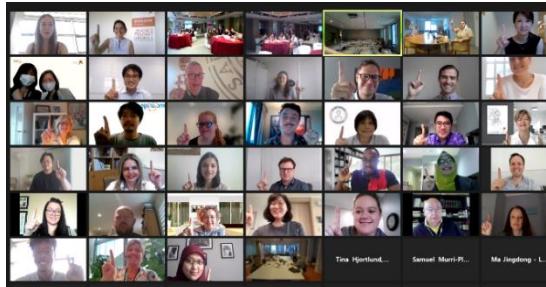
JUNE 2021

Lundbeck 

#1VOICESUMMIT 2021

The clock is ticking for brain health and neuroscience: by speaking together with one voice, we will:

- *Make a bigger and more credible impact*
- *Reach more stakeholders*
- *Use our resources efficiently*



Please share your thoughts and pictures online by using the hashtag #1VoiceSummit

Lundbeck's #1VoiceSummit Online Academy: the clock is ticking for brain health and neuroscience

On 10-11 June 2021, Lundbeck's #1VoiceSummit was back!

The meeting gathered over 75 advocacy associations from 22 different countries, all sharing the same passion: advancing and advocating for brain health and neuroscience. Representatives stemmed from the patient and the healthcare communities. Participants also represented different health/disease areas including brain health, mental health (including depression and schizophrenia), neurology (including migraine, Alzheimer's Disease, Parkinson's Disease) and rare diseases.

This year, Lundbeck's #1VoiceSummit was held mostly online, which allowed for some of the country delegations to meet face-to-face in their own country (in line with local C19 compliance guidelines). To cater for the different time zones, the #1VoiceSummit took place at two different timeslots: as a result, this report will include the feedback from both groups and distinguish the morning from the afternoon session with a respective AM and a PM disclaimer.

Since its launch, Lundbeck's #1VoiceSummit has gathered more than 296 advocacy representatives from more than 193 organizations and 41 different countries.

The #1VoiceSummit has three specific objectives:

- Provide an opportunity for attendees to meet peers and learn from each other's expertise and experience.
- Identify potential areas of collaboration with one another
- Hear about new advocacy insights to help us build sustainable and stronger advocacy communities.

Our 2021 focus: government affairs and fundraising

The clock is ticking for brain health and neuroscience from a policy perspective. As a result, Lundbeck's 2021 #1VoiceSummit focused mainly in two main capacity-building topics: (a)

international policy and government affairs; and (b) fundraising with a focus on foundations.

With the help of interactive panel discussions and hands-on workshops, we found much common ground so that we can continue building a stronger and more sustainable community.

What's in this report?

In this report, you will find a high-level summary of the speakers' presentations. Alongside, we are also sending you the workshops' input. Speakers' presentations and workshop templates have also been sent after the meeting. Should you wish to, feel free host similar workshops with your member associations and use the templates provided.

Let's speak with one voice!

Lundbeck is dedicated to restoring brain health so that every person can be their best. We believe that only by working together will we be able to drive the change needed to address the health inequalities prevailing in this policy area, achieve parity of care and foster neuroscience.



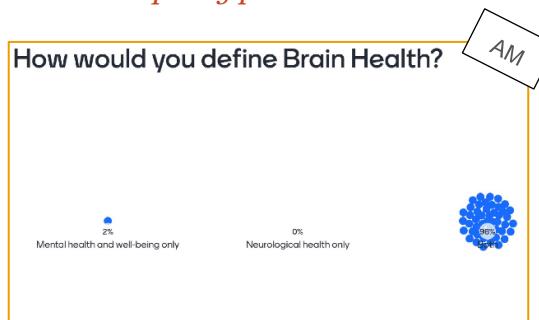
DAY ONE

The keynote speech on the first day of the #1VoiceSummit focused on brain health and neuroscience leadership.

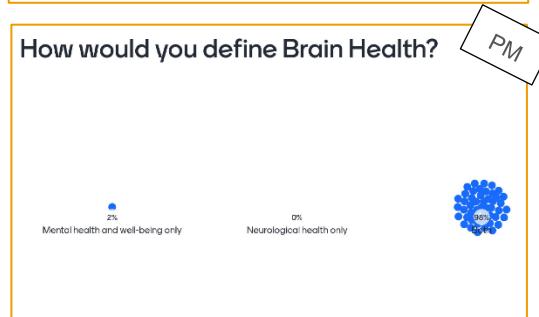
This speech was complemented by a panel discussion on international policy and the importance of a public affairs strategy.

Throughout the day, participants were also asked questions with regards brain health and policy prioritization.

How would you define Brain Health?



How would you define Brain Health?



THE CLOCK IS TICKING FOR BRAIN HEALTH AND NEUROSCIENCE – FOCUS ON POLICY

Prior to the floor being given to the speakers, participants were asked how they would define brain health. A majority of respondents said they defined brain health as both mental health, wellbeing and neurology.

In addition, participants said they would define brain health as follows:

1. *Brain health is at the core of life:* it is essential to our survival and it is the basis of health in general which allows us to live a healthy life. It is the health of our soul. It allows us to be at our best, to be able to cope with life, live to the fullest and to thrive. It is a part of human rights!
2. *Brain health is about one's capability to function daily:* it is about brain function, cognitive function and mental function. It is to have quality of life and vitality. Brain health is about having the brain at its best cognitively and physically.
3. *Brain health is about peace of mind:* it is about feeling good; it is about wellbeing in thinking, in our emotions, in our mood and in our functioning; it's about mental, physical and emotional wellness;

Prof Saxena summarized the definition of brain health by quoting the World Health Organization (WHO):

“Good brain health is a state in which every individual can realize their own abilities and optimize their cognitive, emotional, psychological and behavioural functioning to cope with life situations.... it encompasses neural development, plasticity, functioning, and recovery across the life course.”

Brad Herbert and Saskia Castelain complemented the definition of brain health by defining brain disorders:

“Brain disorders encompass both neurological and mental disorders”.

WHY DO WE NEED LEADERSHIP IN BRAIN HEALTH AND BRAIN RESEARCH?

Shekhar Saxena, Public Mental Health Professional, Department of Global Health and Population at the Harvard T. H. Chan School of Public Health

Prof Saxena, underpinned four main reasons that call for an urgent prioritization of brain health:

1. *The mis-match between the burden of disease (disability and costs) and the resources allocated to it:* despite the fact that brain health conditions disability figures are higher than diabetes, CVD and cancers combined and the heavy costs related to it (in the trillions for mental health alone!), access to services and government investment is quite low in comparison.
2. *Global policy opportunities,* which national governments have committed to delivering on, including:
 - a. The United Nations Sustainable Development Goals, which set a goal for mental wellbeing and an indicator to monitor progress on suicide reduction.
 - b. The WHO's Global Mental Health Action Plan, which was renewed in May 2021.
 - c. The WHO's Global Action Plan on Alzheimer's Disease.
 - d. The WHO's ongoing consultation to the Global Action Plan on Epilepsy and Neurological Disorders, which will set a framework for neurological disorders, which is expected to be adopted in January 2022.
3. *Challenging R&D neuroscience environment:* drug development in neuroscience has one of the lowest probabilities of success. There are two potential avenues to

“We need leadership now more than ever! Brain health leadership is required from both civil society and industry.”

Speakers for day 1



Shekhar Saxena
Public Mental Health Professional, Department of Global Health and Population at the Harvard T. H. Chan School of Public Health



Brad Herbert
Interim CEO, Healthy Brains Global Initiative



Saskia Castelein
Resource Mobilization, Advocacy, and Communications Lead, Healthy Brains Global Initiative



Joke Jaarsma
President, European Federation of Neurological Associations Co-creator of the One Neurology Global Initiative



Simone Boselli
Public Affairs Director, The European Organisation for Rare Diseases

Read more about policy focusing on brain health (mental health and neurology)

- [The United Nations Sustainable Development Goals](#)
- [The WHO's Global Mental Health Action Plan](#)
- [The WHO's Global Action Plan on Public Health to Dementia](#)
- [The WHO's ongoing consultation to the Global Action Plan on Epilepsy and other Neurological Disorders](#)

Read more about facts and figures on brain health

- [Mental Health ATLAS 2017](#)
- [The WHO's Mental Health Action Plan 2013- 2020](#)
- [Global Burden of Disease and the Impact of Mental and Addictive Disorders](#)
- [Scaling-up treatment of depression and anxiety: a global return on investment analysis](#)

move forward: a stronger industry collaboration; and fostering public private partnerships.

"The brain health community has more to gain by working together than by working in a fragmented fashion"

4. COVID19: the impact of COVID19 impacts brain health and may last much longer than expected! Civil society leadership is needed to address the challenges posed by the pandemic (disease competition in terms of policy prioritization and resource allocation) and leverage the opportunity that COVID19 has put on the importance of prioritizing both public health and watching out for wellbeing/brain health.

POLICY FOCUS PANEL

Positioning brain health globally: USD 10 Bn to neuroscience in the next 10 years!

Brad Herbert, Interim CEO, and Saskia Castelein, Resource Mobilization, Advocacy, and Communications Lead, Healthy Brains Global Initiative (HBGI)

HBGI's mission is to improve the lives of people affected by neurological or mental health problems, by driving a model of global, collaborative and inclusive research and increasing the financial envelope for brain health research. HBGI's is therefore pledging USD 10 Bn to invest in brain research over the next 10 years! This is to be achieved by a funding model including government spending, philanthropy and innovative financing.

The Initiative aims to address some of the challenges in brain health research: a growing need to better understand the brain and its mechanisms of function/dysfunction; a siloed approach to research, i.e. too country specific, constrained by disease classification, a disproportionate focus on Western, Educated, Industrialized, Rich, Developed (WEIRD) populations and excluding the needs and expertise of people with lived experience.

To capture policy-makers and industry's attention, HBGI will be officially launched in DAVOS 2022 and a first round of grants can be expected in 2023-2024.

To ensure maximum success for brain health, it requires a collective ownership of a collective narrative so that, together, with one voice, we can make the (business) case for the prioritization and increased research funding for mental and neurological disorders.

"History teaches us that systemic change does not happen overnight. It's important to shape a global brain narrative and movement!"

#OneNeurology Global Campaign

Joke Jaarsma, OneNeurology Initiative

As the global policy momentum for neurology started to grow in the last few years, culminating in WHO's consultation for Epilepsy and Neurological Disorders, so did the need for a united and coordinated voice representing the neurology community.

The OneNeurology Initiative therefore came about in February 2020 and was officially launched in March 2021 in the context of Brain Awareness Week. It is a multi-stakeholder initiative including, [advocacy group partners](#) (e.g. EFNA, EAN, ADI, CoMO, EBC, EPNS, IHS-GPAC, WBP, WFNR, WSA) and supporters (e.g. Lundbeck, Novartis, Roche and UCB).

By working together, the OneNeurology Initiative also aims to: pool resources and expertise to advocate for neurology so as to create a favorable policy environment in which we can make policy-makers accountable and track progress; to empower advocacy groups and share knowledge; to execute campaigns and projects that help deliver on the OneNeurology Initiative mission.

Local advocacy groups are therefore invited to join the OneNeurology Initiative by:

What are your key takeaways from today?



What are your key takeaways from today?



- Becoming an endorser
 - Joining the capacity building [workshop on 29 June](#) to learn more about potential involvement in WHO's Global Action Plan for Epilepsy and Neurological Disorders

Boiling down the ocean? Prioritization in advocacy: the example of the rare disease community

Simone Boselli, PA Director, The European Organisation for Rare Diseases (EURORDIS)

The role of EURORDIS is to promote and put the patient voice at the center of the rare disease debate by 1) engaging patients; 2) empowering patients; 3) advocating for patients.

Strategy becomes all the more important in light of the context below, which to some extent, is similar to the one faced by the brain health community:

1. *The nature of rare diseases*: they are heterogenous, fragmented and low in numbers; this means that people with rare diseases are scattered and isolated; in addition there are few patient “experts” (hence the importance of empowering the patient voice).
 2. *Innovation and research*: not always aligned to public health and health systems’ needs; EU pharmaceuticals innovation ecosystem can be challenging; the regulatory framework can lead to unintended barriers to needs-driven innovation; research can often be fragmented and there is a lack of data interoperability.
 3. *Access to treatments*: treatments are limited and access to them can be unequal and not always affordable across the European Union for example; sometimes there are shortages of medicines.
 4. *Access to care*: to the right diagnosis and care can be limited and delayed.

In light of the common challenges shared by the rare diseases community, EURORDIS led a consultation process (e.g. survey and written consultation) with its member associations to analyze the rare disease landscape and define key priorities for the next

decade. Through that process, EURORDIS landed its strategic pillars to focus on:

1. Research
 2. Access to treatments
 3. Access to diagnosis and healthcare
 4. Social care

“Individual countries cannot face alone the issues related to rare diseases. We need an international/EU policy framework to address the upcoming challenges of the rare disease community for the next 15-20 years.”

CLOSING REMARKS FOR DAY 1

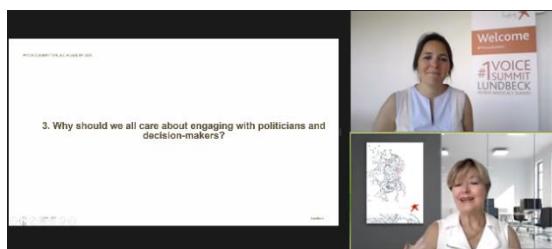
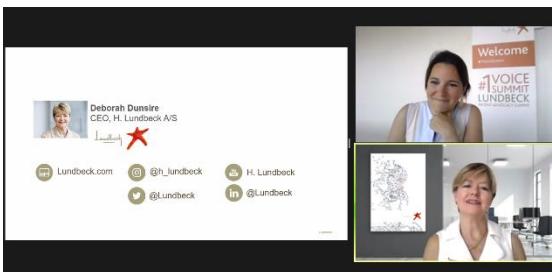
Following the #1VoiceSummit workshops, which focused on defining a local Northern Star, identifying barriers and drivers of policy-makers and of the media with regards brain health and neuroscience, a few key takeaways could be summarized below:

1. Collaboration will be the deal-maker in order to advance brain health and neuroscience.
 2. Despite disease-specific nuances, the brain health community shares similar challenges.
 3. There are many opportunities of collaboration to shape the policy environment, secure the funding/investements in brain health and neuroscience, improve education and empathy to combat stigma on brain diseases.

DAY TWO

Day two of the #1VoiceSummit kick started with a Q&A to Lundbeck's CEO, Deborah Dunsire, which focused on leadership in brain health and neuroscience.

The panel debate discussed fundraising with a particular focus on foundations.



Q&A WITH LUNDBECK'S CEO, DEBORAH DUNSIRE ON LEADERSHIP IN BRAIN HEALTH AND NEUROSCIENCE

The #1VoiceSummit welcomed CEO Deborah Dunsire to discuss leadership in brain health and neuroscience.

Q: Why are you passionate about brain health?

A: The brain is at the center of our being. If we are not experiencing brain health we cannot be at our best. There are more than 600 brain diseases, impacting almost half of the world's population and costing 10% of the world's GDP. Lundbeck is one of the only pharmaceutical companies in the world focusing exclusively on brain diseases and we are tirelessly dedicated to restoring brain health. That's why I am passionate about brain health.

Q: What does leadership in brain health mean to you?

A: Leadership in brain health means working together, with people with lived-experience at the center, while working towards putting brain health and neuroscience at the top of the political agenda so we can execute on parity of care. We all bring different skills and expertise to the table. If we are to lead the world to advance brain health and neuroscience we need to work together and speak with one voice. Lundbeck has more than 70 years of experience bringing forward transformative medicines to people with brain diseases. And collaborating with people with lived experience is critical for Lundbeck to develop the right treatments that deliver on patient preferences and patient-focused outcomes. We are committed to bringing the science forward and we need to work collaboratively and in partnership to ensure that we address real societal and patients' unmet needs.

Q: Why should we all care about engaging with politicians and decision-makers?

A: Politicians have a very difficult job to do! They set policy frameworks, resources and the societal tone on how we discuss brain health and brain disorders. If they are well-informed, they can make better decisions on stigma, access to care and protect people in the workplace for example. Policy-makers are our partners to advance brain health and neuroscience and advocacy

groups have the power to voice their experiences and needs, so that decision-makers are empowered to make the best decisions for the (brain health) community.

Q: What can we do to advance brain health and neuroscience?

A: Be collaborative: although there are nuances to the specific brain diseases, by working together we can advance a common agenda to make sure that our messages are coherent, and we maximize our impact. If we are siloed, we are diluted. By speaking with one voice we can create a common platform. Finally – we need to persist and not give up!

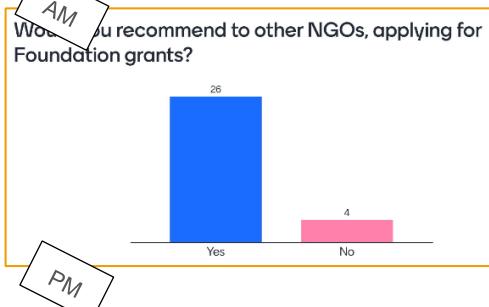
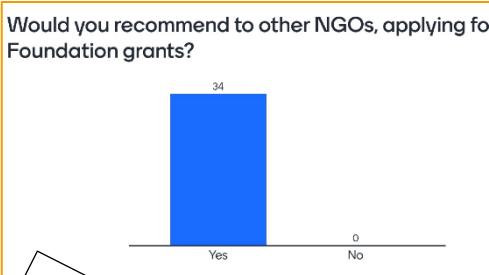
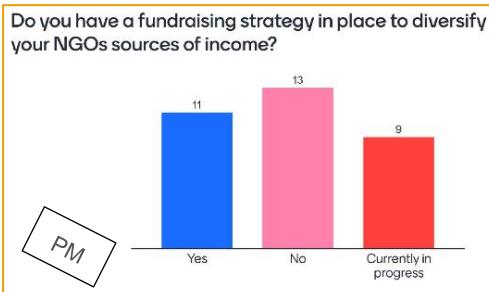
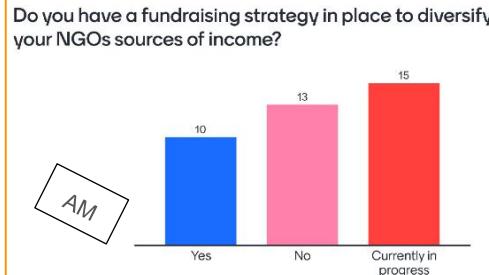
"We are at the beginning of transforming brain diseases. I'm very hopeful that we can understand more about the brain and have a direct impact on those who are in need."

THE CLOCK IS TICKING FOR BRAIN HEALTH AND NEUROSCIENCE – FOCUS ON FUNDRAISING

A sound funding strategy is crucial for the sustainability of the brain health community. To avoid becoming vulnerable to one funder only, or even, a specific industry, it is primordial that NGOs ensure their fundraising strategy is anchored in the diversification of sources of income. Currently, only circa a third of the participants who responded to the real-time survey have an active fundraising strategy that aims at diversifying sources of income.

With this in mind, the #1VoiceSummit wanted to empower the advocacy community on how to include foundations in their funders-mix. But what is a foundation?

A foundation is a private foundation is a non-governmental, non-profit organization or charitable trust. Its principal fund usually comes from a single source, such as an individual, family, or corporation. The fund is managed by the foundation's own trustees or directors. A private foundation does not solicit funds from the public. They have a view on what they want to achieve,



applying to trusts is largely about demonstrating how your particular project can help them achieve their purpose.

Like with any type of funder there are PROs and CONs of targeting foundations:

- PROs: sizeable funding; full-arm's length and independence, provided the reporting is done accordingly.
- CONs: application process can be lengthy with intense paperwork required to apply; high competition.

There are many types of foundations with an interest in brain health. Below is a snapshot of a few of them (organized alphabetically) and by no means an extensive list:

- [Aga Khan Foundation](#)
- [Archwell Foundation](#)
- [Dana Foundation](#)
- [Boston Scientific Foundation](#)
- [Fundação Calouste Gulbenkian](#)
- [Lundbeck Foundation](#)
- [Novo Nordisk Fonden](#)
- [Robert Bosch Stifung](#)
- [Wellcome Trust](#)

FUNDRAISING PANEL

Applying for funding: a foundation's perspective

Jan Egebjerg, Senior Vice President, Grants & Prizes, Director of Science, Lundbeck Fonden (The Lundbeck Foundation)

The Lundbeck Foundation is a commercial foundation, with no owners, that invests in healthcare, where all revenue goes "back" to grants to Danish applicants (close to 100M USD per year). To do so, the Lundbeck Foundation reverts to its brain health strategy.

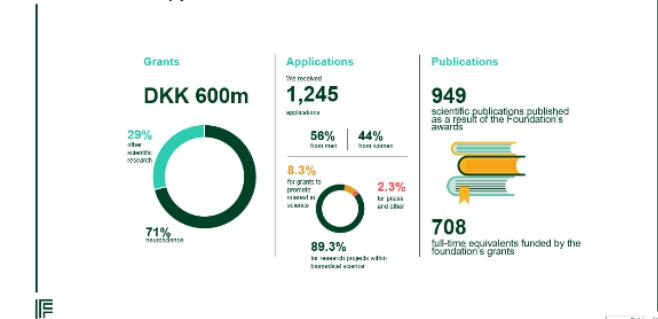
Tips to optimize your grant application, we recommend you answer the questions below:

- 1- *Why:* what is the purpose? What evidence/solid data underpins the need for this grant? How does it fit into the foundation's strategy?

- 2- *Who:* have a well-defined target group;
- 3- *How:* how are you going to measure success and progress (impact and indicators)? How to ensure your project is sustainable once it is executed and the grant is given?

"I can't stress this enough: give us a call! Dialogue is key and the door is always open to have an open discussion about your project, if it fits the strategy, what could be good measures of success"

What did we support in 2020?



Fundraising from foundations: experience from ADI

Rosie Houghton, Corporate Partnerships Manager, Alzheimer's Disease International (ADI)

When it comes to applying for foundation grants, ADI has a clear process in place. ADI provided the following tips:

1. *Do your research:* check similar organizations' annual reports, including in different disease areas; in some countries you will find there is a Directory of Foundations (e.g., [Directory for Social Change in the UK](#), [Foundation Center in the US](#)).
2. *Do your homework:* check the foundation's giving history, audited accounts, read their FAQs, the statuses of the foundation and ensure that your proposal fits the foundation strategy.

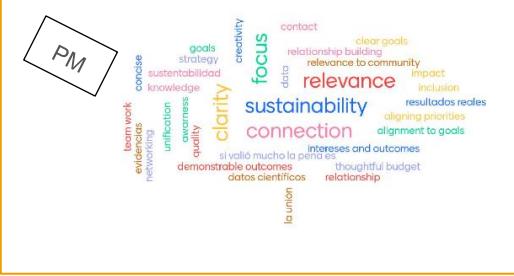
Speakers for day 2



In your opinion, what is the most important thing for an effective application to Foundations?



In your opinion, what is the most important thing for an effective application to Foundations?



3. *Discuss the potential application with the foundation:* call them up for a “Meet & Greet” and to discuss your idea, if it fits with their strategy, what could be optimal measures of success, what roles are to be expected (e.g. is it arms-length like the Lundbeck Foundation? What acknowledgement is required?).

“Speaking to your funder is crucial: it helps build a rapport with them and gives you the opportunity to ask you the right questions so that you’re meeting their objectives and their application guidelines.”

Rosie provided two examples of a best practice and of a lesson learned on ADI's application process:

- Best practice: The Mary Oakley Foundation: in just 3 years, the foundation has increased its grant-giving to ADI by 650%! The relationship has been built by understanding their interests, identifying opportunities to fund specific activities, and sharing regular updates whilst adhering to their guidance on how and when to get in touch.
 - A lesson learned with the MacArthur Foundation: ADI spent significant time developing an application and ensuring the project met all the foundation's criteria by the deadline. Still, by neglecting to have all formal agreements in place with the potential grant partners, ADI was immediately disregarded in step 1 of the selection process.

example, The Time to Change campaign partnered with King's College London to conduct an Attitudes and Behaviors survey between 2008-2016. Ensure that people with lived experience or beneficiaries of your project are co-creating with you the conceptualization and/or execution of the project.

 5. Forward-looking: what is your exit strategy to ensure the sustainability of your project? After the grant is done, what's next?

Fundraising from foundations: experience from the UK

Sue Baker, CEO Changing Minds Globally consultancy

As the leader of the Time to Change campaign in the UK, which was funded by Comic Relief UK, the Department of Health and Social Justice and the Commonwealth, Sue provided a list of tips and focused her presentation on the following:

1. Clearly articulate your purpose: what is the challenge you are trying to address (what evidence is there justifying the need for your project); be outcome focused, i.e. focus on the positive changes that happen for people as a consequence of your activity.

2. Integrate human stories in your proposal: funders are human and will more likely relate to your project if they empathize. This can be achieved by giving your project a human face of people with lived experience and/or of the end beneficiaries of your project.
 3. Have a sharp USP (Unique Selling Proposition): considering the competition to secure a foundation's grant, what makes you unique compared to other NGOs? What credentials set you apart? What impact have you previously had?
 4. Partnership-bids are stronger bids: ensure you bring in other expert partners that can take the lead in areas of potential weakness of yours, i.e. partner with a university to collect and measure impact data. For example, The Time to Change campaign partnered with King's College London to conduct an Attitudes and Behaviors survey between 2008-2016. Ensure that people with lived experience or beneficiaries of your project are co-creating with you the conceptualization and/or execution of the project.
 5. Forward-looking: what is your exit strategy to ensure the sustainability of your project? After the grant is done, what's next?

NEXT STEPS AND CLOSING REMARKS

The brain health community's calendar is a busy one and it is important that participants leverage them and continue the dialogue beyond the #1VoiceSummit:

- 29 Jun: OneNeurology Initiative workshop
 - Jul-Aug: WHO consultation on Neurological Disorders
 - 22 Jul: Brain Awareness Day: watch out for the OneNeurology campaign!
 - 9 Aug: (deadline): IBRO/FENS/SfN Summer grants for Advocacy and Brain Awareness Week
 - Sep: World Alzheimer's Month, with 21 Sep World Alzheimer's Day
 - 12 Sep: International Day for Migraine Awareness (US will focus in June and UK in first week of Sept)
 - 10 Sep-10 Oct: World Suicide Prevention Day and World Mental Health Day
 - Dec: Grants for European Organizations by FENS

What are your key takeaways from today?



AM

What are your key takeaways from today?



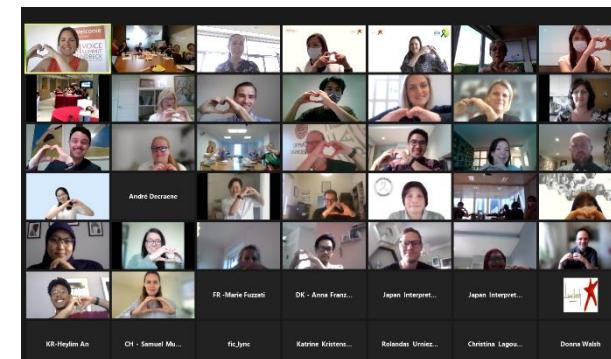
PM

Public affairs campaigns are similar to an orchestra playing: every musician has a role to play, every musician will join at a different time – but together, as a whole, an orchestra plays harmoniously. It is the same with a public affairs movement for brain health and neuroscience: we all bring an expertise to the table, and despite some nuances, alignment in a common goal and narrative will succeed in putting brain health and neuroscience on the map. Three important concepts come to mind in order to advance brain health and neuroscience, which the #1VoiceSummit 2021 has allowed to foster: collaboration in defining a common agenda; an understanding and alignment of the policy environment underpinning a strategy for brain health and neuroscience; and the identification of potential synergies and planning opportunities, including across borders.

THANK YOU FOR JOINING US!

It has been a pleasure spending two days with such committed delegates from advocacy groups around the world passionately working towards the same goal: to improve and restore brain health. Thank you so much for joining us.

We hope to see you at next year's #1VoiceSummit.



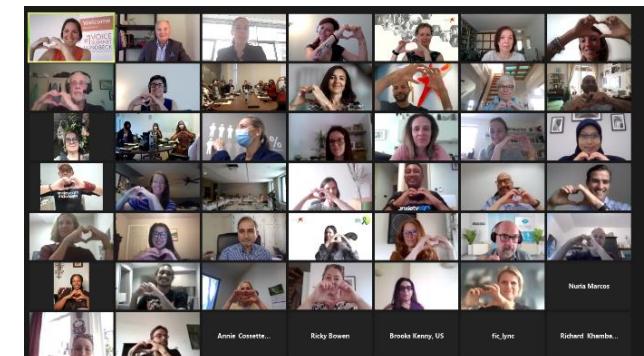
*I had such an amazing two days and felt so inspired and energised as well as learning so much from the other participants – **Rosie Houghton, ADI***

*I am so appreciative of the tremendous effort you and your team put into making such a successful Summit... It was a great opportunity to connect with other...organizations and also to share more about our thought processes/ideas/hopes with you. Thank you for creating the time and space for us to talk, brainstorm and learn from one another. As we all know, brain health is a vast topic which can often seem daunting to tackle, but it's critical that we take the time and effort to chart best practices and next steps, which is what I think we accomplished these past two days. – **Anna Sacket, Clubhouse International***

*I didn't know what to expect but it was even better than I had hoped. We will be reaching out to some of the other participants, for sure – **Teri Chadwick , Clubhouse International***

*We enjoyed it, learned a lot and met knew folks who we are already following up with. The clock is indeed ticking. I like the theme of urgency for action. – **Brad Herbert, HGBI***

*What a great meeting you are having I am glad to be part of it. – **Joke Jaarsma , EFNA***





Lundbeck's #1VoiceSummit brings international and local advocacy groups that are passionate about improving brain health. It provides an opportunity for attendees to:

- Meet peers and learn from each other's expertise and experience.
- Identify potential areas of collaboration with one another.
- Hear about new advocacy insights to help us build sustainable and stronger advocacy communities.

Lundbeck is dedicated to restoring brain health so that every person can be their best. We believe that only by working together will we be able to drive the change needed to address the health inequalities prevailing in this disease area.

The #1VoiceSummit has become a natural extension of our work to improve the lives of people with brain health diseases as well as their families, physicians and the community around them.



*Please share your thoughts and pictures online
by using the hashtag #1VoiceSummit*

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