



#1 VOICES SUMMIT MEETING REPORT

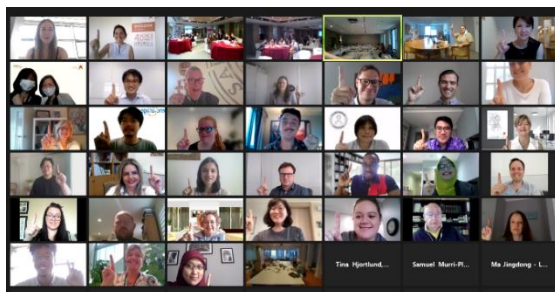
JUNE 2021



#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*



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.

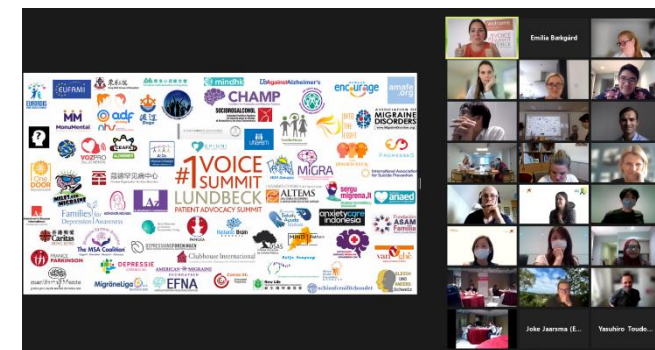
With the help of interactive panel discussions and hands-on workshops, we found much common ground so that we can continue building a stronger and more sustainable community.

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.



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

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?

AM

Mental health and well-being only 2%

Neurological health only 0%



How would you define Brain Health?

PM

Mental health and well-being only 2%

Neurological health only 0%



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.

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

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

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

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:

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](#)

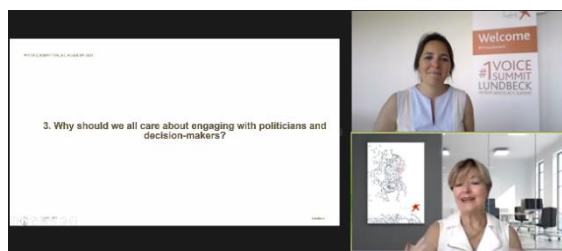
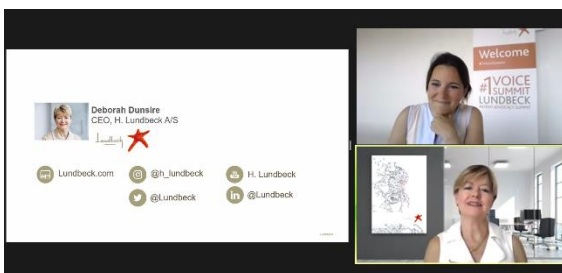
Read more about facts and figures on brain health

- [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](#)

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!

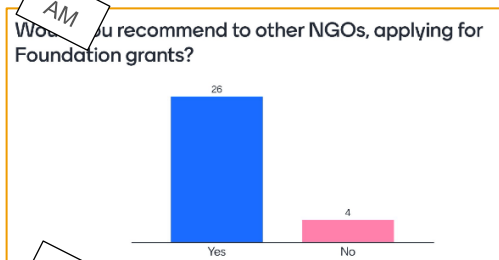
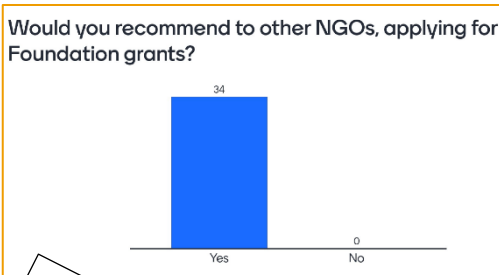
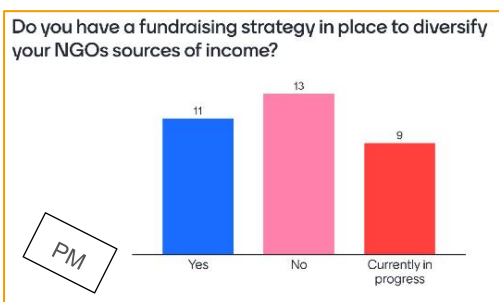
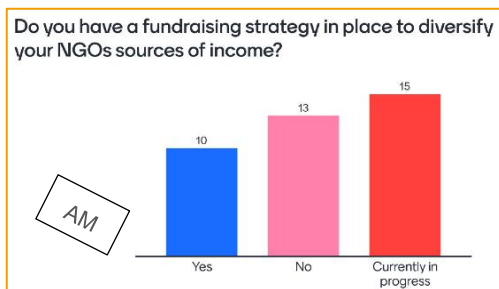
“We are at the beginning of transforming brain diseases. I'm very hopeful that we can understand more about the brain and have a direct impact on those who are in need.”

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 Stiftung](#)
- [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).

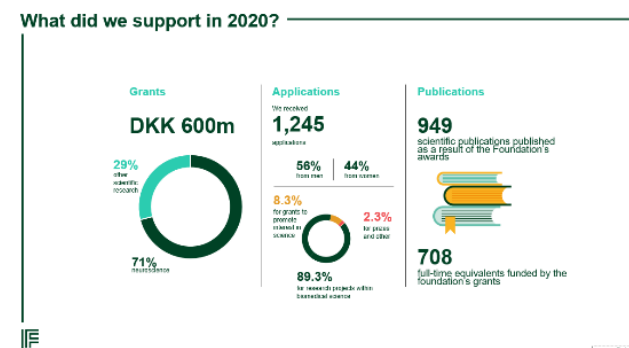
To do so, the Lundbeck Foundation reverts to its brain health strategy.

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"



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.



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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