GLOBAL PATIENT ADVOCACY SUMMIT REPORT
#1VOICESUMMIT
JUNE 2018
On 27–28 June 2018, Lundbeck was delighted to host the #1Voicesummit in Copenhagen for the fifth year.

The theme was ‘One voice – together we will make a difference’, and it was a true pleasure to see so many advocacy groups and patient organizations attending.

This year’s summit had the highest ever number of participants with 61 participants representing 45 patient organizations and advocacy groups from 26 countries.

It provided opportunities for the participants to find common ground and build alliances. Even though the participants came from countries around the world, and work within different disease areas, there was much that united the groups.

Advocacy is an important means of raising awareness of mental health issues and ensuring that mental health is on the public agenda. Advocacy can lead to improvements in policies, legislation and service development. By speaking with one united voice, the global mental health advocacy community can make a difference and help to improve the lives of people living with neurological and psychiatric disorders. The summit aimed to foster coalition building to counter isolation and fragmentation. By finding common ground and speaking with one voice, messages can be amplified and their effect multiplied.

The summit had three specific objectives:
- Enabling patient organizations and advocacy groups to become more empowered actors in national and international health policy arenas.
- Examining opportunities for cooperation with different stakeholders and finding inspiration from best practices.
- Providing an opportunity for attendees to learn from each other’s expertise and experience.

The #1VoiceSummit is a commitment from Lundbeck to make progress for people living with psychiatric and neurological disorders.

The summit was a truly collaborative event, where all participants interacted and were actively involved. This year included inspirational keynote speeches, interactive panel debates, workshops and, for the first time, masterclasses and learning modules. It provided a forum for debate, reflections and knowledge sharing.

This approach reflects Lundbeck’s belief that collaboration between patient organizations, advocacy groups, physicians, societies and the pharma industry is crucial. The combination of shared interest, pooling of expertise and resources with a collaborative approach provides the mental health community with inspiration and energy to tackle mental health and neurological disorders more effectively.

“In a world that is losing trust, patient organizations and advocacy groups are more important than ever. NGOs remain the most trusted institutions and are seen as a source of trustworthy, accurate information in a world of fake news. They are a vital force for change in an increasingly complex world.”

During the introductions we learned that a majority of the participants have a personal connection to mental health and that many are patient advocates because they have a strong commitment to filling a gap.

This report contains a high-level summary of key discussions and contributions from speakers and participants at this year’s summit. Our hope is that we will keep the conversation alive via the #1VoiceSummit hashtag and other means of communication.
The first day of the patient advocacy summit focused on how to find a common framework and create alliances.

The day started with inspirational keynote speeches followed by workshops and a learning session where all groups shared experiences and spotted joint causes called “Voting with your feet.”

BUILDING ALLIANCES AND TACKLING DISCRIMINATION
Paul Gionfriddo, President and CEO, Mental Health America

Paul has had various roles in advocacy and has also served as a full-time elected official. He shared his own story about life with his son who lives with schizophrenia.

Paul shared his experiences and talked about:
• The lack of understanding among experts and politicians
• The importance of recognizing that mental health issues often begin in childhood
• How mental health conditions are unique in only being treated when they reach stage 4 (advanced)
• The need to start listening to, and learning from, the people with these conditions

Paul admitted to being naïve as a policymaker. When a policymaker makes mistakes, they simply move on. He moved on to becoming a mayor and working in the nonprofit sector. However, he couldn’t move on from his role as a parent to his adopted son Tim. At the age of five, Tim showed signs of he’s been trapped in frequent hospitalizations, sometimes incarceration and sometimes homelessness. Nobody seemed to have any idea what needed to be done for Tim at each stage of this serious mental illness.

“Mental health is the only place where we wait until stage 4 until we treat the patient.”

Imagine if we waited until people with cancer entered stage 4 (advanced) before we gave them treatment. From his early years, society let Tim down. He has remained mostly on the streets as a result of a lack of knowledge about how to treat schizophrenia in the same way we treat other diseases.

The world is, more than ever, defined by user demand and it is being shaped more by young people. Communities are being built online rather than in the physical world, which means information is being distributed far more widely than ever before. We need to make use of this opportunity to make changes and put people with mental health conditions at the front and center.
“WORLD MENTAL HEALTH DAY: A COMMON FRAMEWORK”

Deborah Maguire, Director of Administration, World Federation of Mental Health (WFMH), US and Porsche Poh, Executive Director, Silver Ribbon, Singapore

Deborah delivered a presentation that looked at both the past and the future of World Mental Health Day, and Porsche gave some examples of how raising awareness of mental health has come to life in Singapore.

Together they covered:

- World Mental Health Day’s 2018 mission
- A new, unifying visual identity to support worldwide impact
- This year’s theme of youth and young adults
- The opportunity to use the framework of World Mental Health Day to bring together stakeholders to raise awareness and highlight unmet needs

World Mental Health Day aims to educate, advocate and create change. The WFMH would like to encourage advocacy groups around the world to use the information and assets provided by WFMH and use their power locally to make a change.

“The World Mental Health Day campaign brings people together and gives them a unified voice.”

This year is the 26th World Mental Health Day. Over the years there have been 22 different themes on mental health topics, with more than 1,000 events and 108 countries participating. It is inspiring to see how World Mental Health Day has grown with the addition of parades, teaching sessions, clinic openings and much more. By creating awareness, being a unifying voice and spreading hope, it empowers people to take action and create lasting change.

WFMH can speak to broad audiences and achieve worldwide reach. It is supported by the UN, the WHO, and more than 60 nations. It has a 1.3 million reach on Facebook and over 30,000 on Twitter.

“We have a global audience listening to mental health issues. Talk to policymakers. Educate communities. Make a big splash!”

In Singapore, there have been several inspiring local initiatives over the past few years, such as a local Silver Ribbon summit with participants from all over the globe. Silver Ribbon celebrates World Mental Health Day throughout October, raises awareness about mental health issues and encourages everyone to set aside their differences to highlight the opportunities and bring attention to gaps in the mental health system.

The theme for the 2018 World Mental Health Day is youth and young adults. Everyone is welcome to join and become members of the World Mental Health Day community, to share reports and videos from around the world, and to inspire each other.

Online campaign #WorldMentalHealthDay.
GATHERING VOICES AGAINST DISCRIMINATION
Dra. Fátima Viana de Vasconcellos, Director Deputy Secretary, Brazilian Association of Psychiatry, Brazil

Fátima brought some interesting examples of work conducted in Brazil and shared what these campaigns have achieved, including:

- Combatting psychophobia
- “Yellow September” illuminated landmarks like Christ the Redeemer in Rio and parliamentary buildings
- Positive change including anti-discrimination legislation and changes in public health policy

As a psychiatrist with an MSc in Health Sciences, Fátima is active in spreading the fight against “Psychophobia”.

Fátima shared examples from Brazil on how the Brazilian Association of Psychiatry has gathered voices against discrimination and worked with politicians and public opinion leaders through initiatives such as “Yellow September”. Alone they cannot make a change, she stated, but together we can make a difference and increase awareness about mental health issues.

“More is needed but a lot has been done thanks to working together and pooling resources.”

The mental health challenge in Brazil – as in many other countries – is huge. Brazil has a population of 207.7 million (2016) of which 50 million people suffer from mental illness – it has the most anxiety disorders in the world and is fifth in rates of depression (WHO). The country is over 8.516.000km² and in some parts of the country there are no doctors. “Yellow September” is a major campaign raising awareness about suicide, whereby Brazil’s two major religious landmarks were lit up in yellow to draw attention to the problem of suicide. The President’s Palace and Congress were also lit up in yellow, while other initiatives included a walk with the Brazilian army, all wearing yellow T-shirts.
In addition to Day 1’s inspirational speeches, there were three interactive workshops during the day.

**HOW WE WORK TOGETHER TO CHANGE THE WAY POLICY LEADERS THINK – AND ACT**
Facilitated by Paul Gionfriddo, President and CEO, Mental Health America, US

As a former decade-long policymaker, long-time mental health advocate, and leader of the United States’ oldest mental health advocacy organization, Paul used his experiences in facilitating this workshop. It focused on working together locally to influence policy leaders globally, at all levels, to help them make more informed behavioral health policies. Insights and learnings were shared among participants.

Key learnings on how to talk to policymakers and get their attention included:

- Learning about policymakers on a personal level. The first time you see a policymaker, the worst thing you can do is use your five minutes to talk about your issue. Maybe use 30 seconds at the end to talk about your issue—but the first four and a half minutes should establish a connection!

- Getting to know policymakers outside the policy environment is important. Do your research on them before you meet. Find out about education, home towns, colleges and past industry experience to find a connection.

- Being a valuable source of information. If you only have a few minutes, build yourself up as a source of information they can return to in the future. Don’t try to cover all the issues in one meeting. It’s best to choose two or three key topics.

- Asking questions. Leave openings in the conversation for questions and discussions to see exactly what each policymaker is most interested in. Make sure you aren’t just repeating yourself.

- No rambling. It is important to be direct in order to “make the sale”. If there’s a specific ask, make sure you ask it.

- Speaking in one voice. Patient organizations and advocacy groups should not be pitted against each other, but are advised to talk to policymakers together. Collate some messages that everybody can agree on together. Policy change tends to be incremental. You can’t be unsophisticated and just ask for money. Policymakers want to know specifically what the organizations need. You need to be specific.

- Asking the patients what they need. Policymakers make policy based on what they perceive patients want. If you’re trying to be specific, it’s important to know what people want—and how to deliver that. Policymakers think patients are only interested in treatment. But screening tells us that what they actually want is:
  - Information and education – to learn
  - Information and referral to treatment and services
  - Self-help tools such as apps and resources. Young people prefer apps; older people prefer worksheets
  - To connect – engagement with peers, formally and informally

- Being in it for the long haul. It is important to remember that changes may take a decade and we’re in it for the long haul. Politicians are in for the short haul, so they want quick wins and things they can do to get credit in the short term. They are not focused on the big picture. It’s important to be specific – offer little pieces for them whereby they can do something small that’s meaningful.
ENGAGING WITH GLOBAL ALLIANCES FOR MENTAL HEALTH: FOCUSING ON WORLD MENTAL HEALTH DAY

Facilitated by Deborah Maguire, Director of Administration, World Federation for Mental Health (WFMH), US, and Porsche Poh, Executive Director, Silver Ribbon, Singapore

This workshop focused on how the participants could engage further, not only in local but also in global alliances for mental health. One initiative is the Global Alliance for Mental Health Advocates, which will be launched by Singapore-based Silver Ribbon during this October’s Global Mental Health Summit 2018 in Singapore.

Great input was also shared on how the WFMH can support local initiatives and ideas, that builds on, for example, World Mental Health Day. There was emphasis on the importance of bringing everyone in the community together to spread the work, limit costs and ensure success.

What can WFMH do to assist patient organizations and advocacy groups in creating good campaigns?

- Creating a joint platform for increased awareness. Membership of WFMH is free of charge
- Providing organizations with contacts that might want to join their campaign, creating a global community
- Sharing promotional materials and videos
- Helping the patient organizations and advocacy groups create awareness around local initiatives and events
- Taking inspiration from Silver Ribbon by promoting “what is happening in our country right now”
- Inviting employers to pledge: “I do provide equal job support”, “I do build the right capabilities”, etc.
WORKING TOGETHER TO INFLUENCE FUTURE TREATMENTS

Patients, patient organizations and advocacy groups are increasingly involved in all aspects of healthcare. The workshop gave an opportunity to discuss where and how patients can influence new treatments, and how patients’ perspectives can become more present in the development of new therapies. It was a learning session on how stakeholders can better share knowledge and provide insights on patient needs, and on how to improve the patient experience in developing new and better treatments.

Several interesting discussion opportunities arose where we addressed the challenges for increased patient involvement to create better treatment for people living with psychiatric and neurological disorders.

One of the key learnings was that there are many more interaction points at which patients can influence future treatments than the groups initially thought. However, there is still some way for the industry to go to ensure more input from patients.

Engagement in research
- Participants had limited experience in engagement with research in the pharma industry
- To encourage engagement, “a research roadmap” could explain the different stages and kinds of research, and how it could benefit patients
- Knowledge of what research had been undertaken, and where and how, would be valuable for the groups
- It was noted that knowledge about, and participation in, research could build hope for the future

Further, it was noted that groups within the mental health arena might be able learn from both the rare disease and multiple sclerosis communities with regards to engagement in research

Science education
- There was concern that not only do patient organizations and advocacy groups find it hard to stay current but that many primary care physicians have the same problem
- This raised the issue of where patients go to find accurate, credible information, and the need to debunk some of the myths perpetuated on the internet
- The difficulty in understanding some of the complex technical language used by healthcare professionals was mentioned
PATIENT INSIGHTS
Christoph Von der Goltz, Head of Medical Affairs, Lundbeck

Following up on the workshop “Working together to influence future treatments”, Christoph shared some of the different ways in which Lundbeck is engaging patients, patient organizations and advocacy groups in the company’s research, including:

- Data-driven insights: Data helping the understanding of biology and targets for the development of future medicines
- Focus groups: Insights helping the understanding of patient and caregiver unmet needs for treatment and disease management
- Patient reported outcomes: Measurements helping to demonstrate a treatment effect on patients’ health, quality of life and functional status

Collectively, we can make a difference, ensuring we adopt a patient-centric approach in everything we do, to ultimately deliver innovative and best-in-class medical care to people living with mental health disorders.

Your voice matters!

VOTING WITH YOUR FEET
All

The last point on the agenda for Day 1 before the dinner was the joint learning session where all groups shared experiences and spotted joint causes called “Voting with your feet”. The exercise gave the groups the opportunity to step into a big square and share experiences and prioritizations with the whole group.
DAY 2

Day 2 of the summit focused on strengthening advocacy capacities.

It kicked off with a panel debate with “best in class” advocacy stories and also included Masterclass and learning modules where the delegates could work on specific cases and gather knowledge to bring back to their respective organisations.

PANEL DEBATE AND CASE STUDIES ON BEST IN CLASS ADVOCACY
Alex Wyke, CEO, PatientView, UK, Rob Ramjan, CEO, One Door Mental Health Australia, Australia, and Chiara Piletti, International Aspects Spokesman, Coordinamento Toscano delle Associazioni per la Salute Mentale, Italy

PatientView carries out regular surveys of patient groups, and Alex shared examples of best practice from mental health, as well as from the wider disease community.

In a PatientView survey that will be published later this year, 42% of groups said they had a fundraising strategy, while 70% lack funds and 9% worked with regulatory authorities. According to the survey, the challenge is that national health technology authorities do not trust patient organizations and advocacy groups. Therefore, the advice when working with regulatory groups is to take a united approach, find common ground and work as one organization, which can be more effective.

The survey showed that 48% of the groups said that one of the biggest hurdles was lack of research. However, patients have very little idea of how the pharma industry works. Patient groups can act as a bridge between the patients and the pharma industry. The James Lind Alliance is a great example of patient input driving research.

Chiara shared some of her experiences. Italian law requires voluntary organizations to be involved in patient services. Coordinamento Toscano delle Associazioni per la Salute Mentale runs a congress every year, which focuses on putting patients at the center of care.

Rob shared “10 learnings in 10 minutes” from his organization in Australia (it was actually 11 learnings).

Rob’s learnings:
1. The group must have a clear mission
2. Grow your power base in order to wield influence
3. Be patient as change is slow
4. Have a strategy
5. Build personal relationships with policymakers
6. Incorporate lived experience
7. Have great governance but where possible have people with lived experience
8. Develop real partnerships (not just asking for money) and look beyond the usual suspects for partners
9. Diversify your funding sources and, where possible, build up a financial safety net
10. Build a strong structure
11. Do not try to do too much
MASTERCLASSES AND LEARNING MODULES

For the first time in the history of the summit, this year introduced masterclasses followed by interactive learning modules.

Six important topics were on the agenda during the masterclasses, followed by in-depth discussions and individual work in six learning modules.

All materials and presentations from these sessions are available upon request: NIAV@lundbeck.com.

1. Appropriate governance and management structure

Patient organizations usually get started based on the passion and commitment of one or more advocates. Early on, governance issues aren’t usually the focus, but they should be addressed as soon as possible to ensure the organization gets off on the right foot.

Good business practices are essential for:
- Complying with applicable laws and regulations
- Being taken seriously by funders, regulators and patients
- Creating the structure needed to achieve your mission

This part might feel like “homework” but it is important because it helps to gain respect from potential funders, lawmakers and members. It is essential to understand how local and national tax laws apply to your group – and what resources are available to guide you in this area.

It is also critically important to form a board of directors if you don’t yet have one. If you do this, you must decide how big a board you need, and what types of expertise and perspectives you want represented on your board.

Further, it is essential to think about creating a staff team (if you don’t yet have staff) or expanding your team if you already have some employees. What are the essential functions you need filled, and what more could you do with additional staff?

Finally, you also need to decide your fundraising policy. Who will you raise money from (individuals? NGOs? Corporations?) and how will you establish independence from your funders? Once you develop a policy, it is critical that you make it available to those who want it, on paper and/or online.

2. Budgeting for success and maximizing funding streams

Starting and building an organization is always a learning process – you’ll try some things that work, and others that won’t. Despite this natural uncertainty and unpredictability, it’s important to be as thoughtful as possible in deciding which activities, programs and efforts your organization will engage in, how much money you need to carry them out, and what will be your most effective ways of raising funds.

With sound budgeting practices, you will:
- Increase stability
- Achieve your goals faster
- Raise more money
- Fund more projects

Both large and small non-profits raise funds through walks, runs, bike rides and other community activities. For example, the American Foundation for Suicide Prevention holds “Out of the Darkness Community Walks” in hundreds of cities across the US, and the American Cancer Society holds more than 5,000 “Rally For Life” events annually in communities across the US and in more than 20 other countries.
Events like these can work for small organizations too! It’s a process of determining what you want to do, what’s possible, what must be done now, and what can wait. Then it’s a process of determining how much money you need to tackle the urgent things, and how you’ll raise those funds.

3. **Building a collaborative network**

You can’t do it all – every organization needs allies and collaborators to achieve its goals.

The benefits of a strong network include:

- Dividing priorities and projects
- Gaining expertise
- Speaking with a louder voice
- Increasing your collective strength and influence

Those who collaborate have the best chance of success, so it’s important to think very closely about who you’re going to collaborate with! They won’t necessarily be 100% friends. Sometimes it is more of a “Collabettion” – collaboration and competition. And that is ok!

The first step before determining whom to engage is to address why you would engage them. So, what are your organization’s primary goals? Patient awareness and education? Patient support services, funding research, influencing laws/policies? You may answer one or all of the above – in any case, determine which one or two goals take priority over the others.

Next, begin to think about the organizations that could help you achieve your goals. In evaluating organizations, size and notoriety may be the first factors you think of, but consider other factors too, such as how broad an organization’s membership is, how strong its communications channels are, how much scientific expertise it has, how influential it is on public policy, how willing it may be to work with you, how easy or hard it could be to work with, etc.

Finally, consider what you would do with other groups once you make contact. You may seek an informal relationship in which you keep each other apprised of your respective activities, or it may be something more formal – collaborating on an education/awareness campaign, communicating to its members/patients, devising offerings to your members or partnering on policy/lobbying efforts.

4. **Developing and future-proofing your advocacy strategy, and influencing external decision-makers**

Once a patient organization or advocacy group becomes established, it can have a real impact on the laws, policies, regulations and rules that affect the group’s members – and others with the condition.

A strong strategy will help to:

- Enhance effectiveness
- Grow partners and members
- Raise more money

One example is Mental Health America, a leading group advocating for public policies that promote mental health and address mental illness.
Mental Health America was a driving force behind legislation passed by Congress in 2016 – the Helping Families in Mental Health Crisis Act – to improve mental health services and support. To support its policy priorities, Mental Health America uses targeted communications, expertise, grassroots mobilization and relationships with lawmakers.

Effective advocacy requires planning and preparation. The first question to ask is what changes are needed:

- More government funding for research, awareness or prevention efforts?
- Stronger public policies that make it possible for patients to get adequate health insurance or to access the care they need?
- Stronger workplace policies that protect patients from discrimination?

Be aware that you can't change everything. Focusing on two or three advocacy priorities will make you much more effective than focusing on the whole gamut of issues.

Once you decide your priority issues, the next question is who can make the change you need:

- National legislators?
- Local elected officials?
- Companies and other employers?
- Organizations representing doctors, hospitals or insurers?

These are your primary targets. Based on these, you should find out what your most effective tools are for influencing them.

It's important to prioritize the assets you bring to the table:

- Do you, or people you know, have personal relationships with influencers?
- Do you have a large group of volunteers who can call and write the influencers?
- Do you have technical or medical expertise to contribute significantly to the issue/debate?

5. Effective marketing, communications and content development

Regardless of your goals (and you should know what those are), you'll be more effective at accomplishing them through smart marketing and communications efforts. Ensure your voice is heard. You must be strategic and purposeful in your communications to the outside world.

You must also have the right content for the right channels and audiences.

- Firstly, choose your issues. Don't try to boil the ocean; you need to focus.
- Ask yourself what you are trying to say. Your messages should be simple, but they must go beyond declaring that a particular disease or condition is bad. Your message could be about general awareness, or more particularly about education. It could be a call to get screened, or a call for more research or support.
- Secondly, target your efforts. Some people are more likely to support your efforts, so target them. You won’t be as effective if you don’t develop some champions to help you.
• Ask yourself who you’re speaking to. The public at large? High-risk populations in particular? Patients and their families? Influencers?

• Thirdly, motivate your members – advocacy is kindly looked upon thanks to ample media coverage. But some people hate the thought of politics. Find out what triggers the members.

• Make sure to identify who you want speaking for your organization. It’s probably you, but who else could: board members, other staff, patients/advocates?

6. Maximizing the value of social media and how to use analytics

When thinking about social media engagement, the first questions to ask are identical to those for developing your marketing/communications strategy.

Your social media plan will be part of your overall marketing and communications plan. Social media platforms can be seen as “owned” channels that, like your website, are largely under your control.

But the ease of publishing a Facebook post or sending out a tweet – and the brief lifecycle of each – make it hard to target audiences and break through the clutter.

What you communicate on social media, and where you communicate it, will of course depend on what information your audiences want, and where they want it.

Social media should be a central part of your communications efforts. With robust engagement on social platforms, you’ll:

• Leverage the power of “owned” media channels
• Engage in two-way dialogue with key audiences
• Foster greater engagement
THANK YOU FOR COMING
It has been a pleasure spending two days in the company of committed and passionate representatives from patient advocacy groups working towards the same goal: to improve conditions for people living with psychiatric and neurological disorders.

We hope to see you at the Global Patient Advocacy Summit 2019.

The Global Summit was fantastic once again. As it was my second time, I consolidated a number of relationships with my counterparts across the world. The information sharing was one of the highlights, and it was quite inspiring to hear of the work that Lundbeck’s partners are achieving with your support.
Tony Stevenson, MIFA, Australia

It was a pleasure spending that time at Lundbeck, getting to know you and your colleagues a little, and getting to spend time with patient advocates from around the world. There are so many bright and dedicated people in our field. I hope that everyone at Lundbeck takes pride in its efforts to support patient advocates, and to make occasions like this possible for them to come together and learn from one another. You’re doing important work, and I hope you take pride in it.
Paul Gionfriddo, Mental Health America, US

We sincerely appreciate the support received to attend this meaningful event and opportunity to exchange ideas with speakers & delegates.
Porsche Poh, Silver Ribbon, Singapore

I am writing to thank you for the welcome and good treatment you gave us during these work days. I felt very good at the event and with all the guests. I congratulate you and the company for the excellent organization.
Dr. Alberto Trimboli, World Federation for Mental Health, Argentine

It was a pleasure to participate and collaborate with your excellencies in this great and successful event. You can continue to count on us for future editions and actions, as well as, we would like that you can be our further partners in national and international actions organized by our National Federation.
Miguel Durães. FamiliarMente, Portugal

There is excellence happening in many places and the opportunity to hear and learn is a wonderful benefit. There was such a great sense of comradeship at this year’s Summit.
Post-summit survey
The aim of the #1VoiceSummit is for international and local patient advocacy groups to meet and build relations, to exchange knowledge and insights and examine opportunities of cooperation with different stakeholders. In addition, participants can gain inspiration from best practices in the wider disease community in order to raise awareness about, and making a difference for, people living with mental health and neurological disorders.

People living with mental health and neurological disorders are our joint field of interest. For many years Lundbeck has been committed to addressing challenges within psychiatry and neurology and ensuring relevant support to patients.

The #1VoiceSummit has become a natural extension of our work to improve the conditions of people living these disorders, their families, physicians, and the community around them. We call it Progress in Mind.