

SANE 2019 International PANS Conference: Pooling Knowledge – Moving forward

Event Evaluation



Background:

SANE hosted an international conference on PANS and immunopsychiatry in Malmö, Sweden October 3rd-4th 2019. The conference was the final phase of a three-year project mainly financed by Arvsfonden (the Swedish Heritage Fund). The conference planning began in January 2017 and was ongoing for more than 2.5 years.

PANS (Pediatric Acute Onset Neuropsychiatric Syndrome) and its sub-group PANDAS are still largely unknown and poorly understood diagnosis. The main conference goal was to bring both national and international clinical and research expertise together into a forum where medical and mental health professionals from Sweden and other countries could learn from their knowledge and experience. A second goal was to provide networking opportunities that could lead to collaborative projects in research between Sweden and other countries. The third goal was to empower parents. Having a child who suffers from PANS can be extremely isolating, even with opportunities to connect online. The conference sought to 1) provide parents with an opportunity for personal connection and support; and 2) equip them with expert advice and knowledge they could take with them to further their child's care.

Significant thought and consideration went into choosing the ideal mix of speakers and topics to support our goals. It was imperative to us that the patients' voices be heard. We wanted to both "teach and touch" the delegates. A successful conference to us therefore meant that the delegates would leave the conference informed, connected and with genuine insight into the lives of those affected by PANS.

The conference attracted a total of 360 participants. Of those, approximately 200 were healthcare/medical professionals and about 120 were parents or other relatives. There were also a few adults with PANS and the rest fell into the category of "other." This included, for example, teachers, laboratory personnel and scientists from pharmaceutical companies. This is an estimation. We don't know exactly who everybody at the conference was and why they were there.

There were some in attendance who had dual roles. For example, being a doctor and a parent to a child with PANS.

There were two evaluation forms provided to participants along with the welcome materials. One form was designed for all participants and the other was intended for medical professionals. The latter was provided by LIPUS, a non-profit, independent, subsidiary company owned by the Swedish Medical Association, who certified the conference. We prompted the delegates throughout the conference to fill out the evaluation forms applicable to their participation.

Of the 360 participants, 199 completed the forms for everyone. Some provided many details. Others were more schematic. 122 filled out the LIPUS-forms for medical professionals.

We received an outpouring of positive verbal feedback throughout the conference. These sentiments were reinforced and reiterated by the written evaluations.

We are proud to report that we met and exceeded all conference goals. With this said, we also see room for improvement. We are incredibly inspired to do this again. However, we will bear in mind – if we are able to do this again in two or three years – that you can never satisfy everybody.

We want to thank *Arvsfonden*, who provided the primary funding for all phases of this project, and our other partners, *Event in Skåne* and *Malmö Stad*. We are also grateful for support provided by *Vetenskapsrådet* (the Swedish Research Council).

We want to thank the speakers for their willingness to travel and give their best; our committed volunteers; and all of you who came to learn and network, whose presence made this such a great experience. You helped create a fantastic atmosphere!

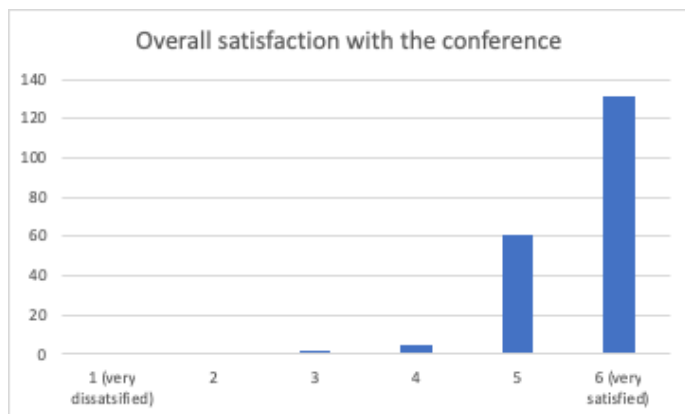
Gunilla Gerland
Chair of SANE Sweden

SANE – Föbundet autoimmuna encefaliter med psykiatrisk presentation

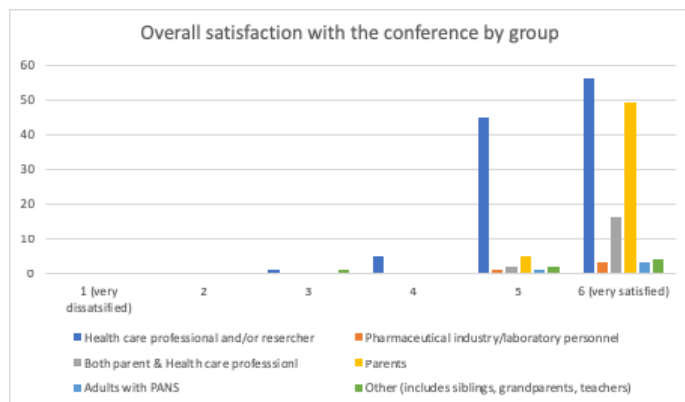
Results from the Evaluation Forms

Overall satisfaction

The overall satisfaction with the conference was very high. Of the 199 evaluations returned, 131 attendees gave the highest rating possible on the scale from 1 to 6, indicating that they were “very satisfied”. The average rating was 5.6.



We also looked at each category of those participating and how satisfied they were as a group. This is not a comparison between groups since the groups are not equal in numbers. It is noteworthy that there was not a significant difference in levels of satisfaction between the groups, although parents were more willing to rate a 6 than a 5.



Was Information Learned Useful?

Those attending in a professional role had two questions specifically aimed at them. The first was, “Did you learn any useful information that will help you in your work life?” This question had 110 responses in total.

- **103 professionals answered “Yes”.** Many added comments such as “a lot” or “it exceeded my expectations” and similar.
- **7 stated that they “partially” or “somewhat” learned useful information.**

The second question directed at professionals was whether they networked during the conference. The question read, “Did you network and make connections with other professionals, and if so, do you think this will be useful in your work?”

- **76 answered “Yes.”** Some added comments such as:
 - “I did connect with other professionals, which will hopefully lead to collaboration in the future.”;
 - “Very useful for our future work with children with autism and PANS”;
 - “I met several people who were new to me and hope we will have professional exchange”;
 - “I got useful information on how to seek help from colleagues and where to refer patients”.
- **8 answered they partially or somewhat networked.**
- **15 stated that they didn’t network** or make connections. Several of those who said that they didn’t network or make useful connections, offered explanations such as:
 - “I am not good at networking”;
 - “No, but I know now who to contact”;
 - “There was plenty of opportunity if I would have wanted to”.

Another explanation offered for not taking advantage of networking opportunities was that they work with administrative tasks in the healthcare system rather than with patients.

We conclude from this feedback that the conference successfully met the goal to provide an opportunity to learn and network. In fact, one could say that the results exceeded our expectations.

“I meet these patients, often with an inconclusive diagnose.

Here I found much knowledge, optimism and new contacts. One of the best conferences I ever have attended”

(Doctor)

“Really well-organized and well-run”

(Pediatrician)





We asked all the delegates: **If you were to use one word to describe this conference, what would it be?**

To the left: This graphic illustrates the feedback we received. The size of the word represents how frequently it was contributed.

To the right: This graphic illustrates the feedback from professionals.

What Did the Conference Mean to parents?

Two questions were specifically aimed at parents. The first one was, “What, if anything, did it mean to you to be part of this event?” There were 82 parents who answered this question.

Hope is mentioned by the majority. It is mentioned either as a single word or with an explanation that it was very hopeful seeing so many clinicians and researchers from all over the world, who are interested and engaged in PANS research and treatment. Some elaborated that it gave them hope that their child will get better and/or hope that knowledge of PANS and treatment options for PANS will increase.

Parents appreciated the **sense of community** the conference provided and **feeling less alone**. Their responses often returned to the theme of the **importance of meeting with other parents** in person and having the opportunity to share stories. One parent wrote, “It means very much to be a part of something when your life is so lonely and isolating otherwise”. Another parent felt “included, understood, and empowered”. While another parent reported having “more energy to carry on struggling”.

Parents welcomed acquiring **better knowledge and being better informed**. They noted how being part of an event, where so many doctors and researchers meet and connect, felt important. They valued the opportunity to directly interact with such caring and committed PANS doctors, who made time during meals and/or in the evenings after the conference. One parent commented, “Seeing progress unfold is very inspiring”. Some parents expressed an interest to increase their efforts to advocate for PANS awareness and treatment.

The second question asked whether the parallel seminars aimed at parents were useful to them. Several replied that yes, they were. However, several mentioned that they felt frustrated missing the seminars in the main hall (even though they knew we filmed these seminars and will make them available online). While the intention was to give the parents something that was exclusive for them, that was



Above: This graphic illustrates the feedback from parents.



not how it ended up being received. We feel this is important information that should be taken into consideration in the future. It is not a good idea to have parallel seminars at this type of conference if it has the potential to create a feeling of missing out.

Reasons for Attending and Whether the Conference Met Expectations

We asked all attendees why they chose to participate and whether the conference met their expectations.

Parents and Adults with PANS

Almost all parents who replied said they chose to participate to 1) learn more about PANS in order to better help their child; and 2) to become better informed for future contact with doctors.

All who responded reported that the conference met their expectations. Several said it exceeded their expectations and others elaborated with additional, positive exclamations such as: “Fantastic!”, “... and much more!” etc.

Parents were additionally motivated to: “Meet other parents, and to learn what happens in other countries”.

**“I want to have the same information
as my child’s doctor.”**

(Parent)

**“To meet clinicians, hear about the most
effective treatment, and share experience”**

(Adult patient)

**“Quality all over – important that people
come together to discuss the subject.”**

(Parent)

**“It has exceeded my expectations and
I am so happy that there are lots of
health care professionals here”**

(Parent)

Professionals

It was rewarding to see the conference and its offerings attract professionals with a wide range of backgrounds. For example, while some already work as clinicians and/or researchers in immunology, psychiatry etc., others had very little experience with PANS.

Many professionals attended the conference in order to learn more about something specific. For example, treatment. Several said they wanted to improve their knowledge of PANS and/or understand the relevance of the diagnosis in different countries. Some researchers in immunology and psychiatry stated they specifically attended in order to network. The purpose for one doctor/researcher was, “To increase my competence and facilitate better care at my clinic”.

There were only two professionals who responded to the evaluation who said the conference did not completely meet their expectations. One of them wrote that it “almost” met their expectations, but they didn’t elaborate where it fell short. The other respondent, who is a specialist in child and adolescent psychiatry, commented, “I was hoping to get more knowledge about how to manage clients clinically. Not quite met my expectations”. Elsewhere in their evaluation, this attendee shared that what



they liked most about the conference was, “The humbleness at the conference, how difficult this area is”.

Others mentioned the complexity of PANS. One doctor’s takeaway was: “It was great – and confusing”.

We, at SANE Sweden, often struggle with the complexity of PANS when we inform others about it. We can appreciate how confusing and overwhelming this diagnosis can be to those who are new to it.

Aside from those two professionals whose expectations were not met, all other professionals said the conference met or exceeded their expectations. They often added enthusiastic qualifiers such as “more than satisfied!”.

**“I’ve been doing research in PANS and
autoimmunity, hence attending this conference.
I am taking new knowledge with me and will
bring this into my clinical work”**

(Researcher)

**“I needed an update of knowledge
– and I’ve got it! Thank you for a
really great and useful experience”.**

(Child psychiatrist)

**“I wanted an update on where the science
stands today, my expectations was really met”**
(Psychologist)

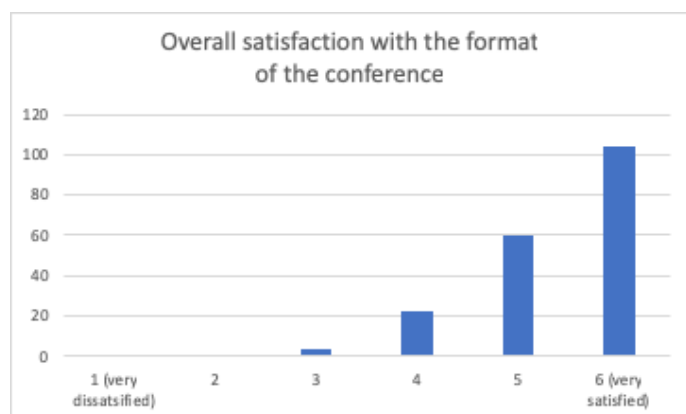
**“A new topic I wanted to learn more about,
and I really did!”**
(General Practitioner)

“Better than I expected. I’m impressed”
(Psychiatrist)

To conclude, it is a tremendous success to have the vast majority of attendees have their expectations either met or exceeded. This is particularly true when one considers: 1) the diverse backgrounds of those in attendance (e.g.: parents, grandparents, adults with PANS, siblings, doctors of different specialties, basic researchers, psychologists, occupational therapists); and 2) those in attendance ranged dramatically in their knowledge of PANS from hardly knowing anything to having worked with the diagnosis – or even researched it – extensively for years.

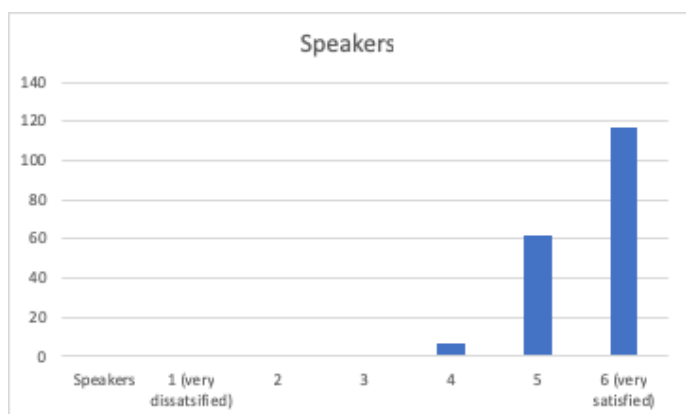
Satisfaction with Different Aspects of the Conference

We asked the delegates to rate their satisfaction with certain aspects of the conference.



Overall satisfaction with the format

Satisfaction with the format of the conference (i.e. breaks, lunch, dinner, lengths of lectures). The average is 5.4 with 191 replies.



The speakers and the quality of sessions

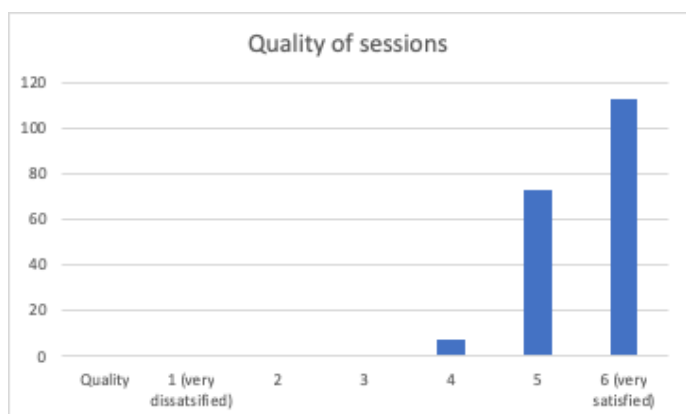
Satisfaction with the speakers. The average is 5.6 with 186 replies.

“I liked the broad approach and the expertise of the speakers.”

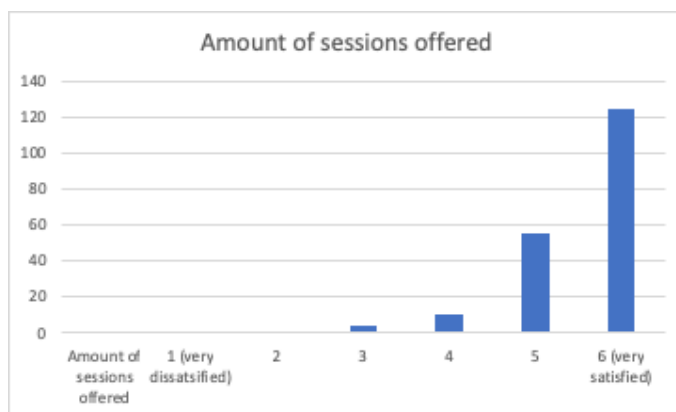
(Child psychiatrist)

“A good mix.”

(Child neurologist)



The quality of the sessions. The average is 5.5 with 194 replies.



The amount of sessions offered. The average is 5.6 with 194 replies.

The consistency in positive responses to these individual questions are bolstered by the responses to the open-ended question asking which elements of the conference the attendees liked the most and which event or speaker they were most pleased with. The attendees endorsed our efforts with comments such as:

- “All of it!”;
- “Everything!”; or
- “I can’t pick something, it was the wholeness that made it so good”.

These and similar comments were contributed consistently across all categories of attendees (parents/relatives, adults with PANS and professionals). Several replied: “Excellent speakers” and “I liked all the lectures”.

Many attendees made the effort to mention one or more speakers, whose presentations they particularly appreciated. It was gratifying to note that all speakers were mentioned by someone. This feedback validates our earliest efforts planning the conference. We successfully achieved our goal to provide *high caliber content* with *broad appeal* to a *diverse audience*.

“I liked the mix between clinical and basic research.” (Doctor)

“It was incredibly interesting!” (Researcher in microbiology)

“Lectures were excellent, composition excellent.” (Psychiatrist)

“I liked the diversity.” (Parent)

“It was a great team of experts!” (Doctor)

“The HIGH quality of speakers, really front-line research.” (Child psychiatrist)

“I liked all events equally, a good mix.” (Researcher in immunopsychiatry)





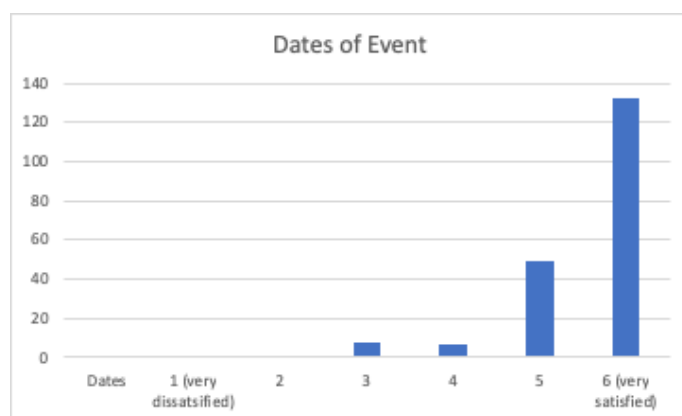
Dislikes

The evaluation form asked “What, if anything, did you dislike about this event? The vast majority of all attendees replied, “Nothing” or left it blank. However, some mentioned specific events. One example was that one of the speakers cancelled and was not replaced by someone else from the speaker’s clinic. This was, of course, beyond our control. We received the cancellation the day before his speech. We think we adapted as well as could be expected under the circumstances. We were fortunate to have another speaker graciously step in with that short notice to discuss Occupational Therapy and PANS.

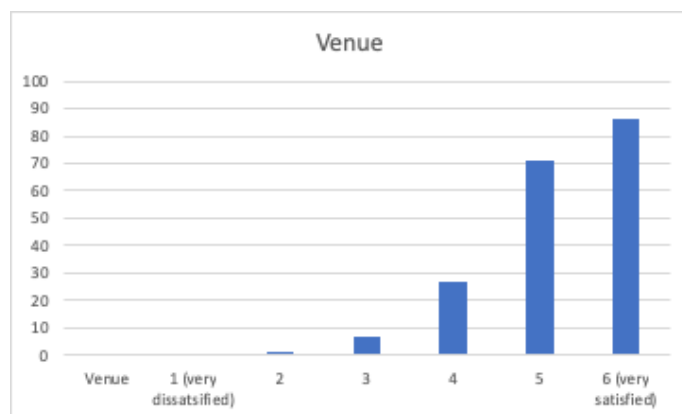
The food was mentioned by some as a negative, but others rated the food among those things that they really liked about the conference. We must conclude that with 360 attendees, you can’t please everyone’s taste in food.

Several people mentioned the fact that the conference hall only had one door. This made it disturbing when people entered and left during the presentations. We agree this was a problem. This is a detail we will remember to note in the future when assessing venue options.

Some didn’t like the venue (in general), but as you can see below, many did like it. Some stated that the dates of the conference were inconvenient, particularly because it included a Friday. However, when reviewing the complete results, the dates of the conference received a high rating in terms of satisfaction (see below).



Satisfaction with the dates of event was quite high. The average is 5.5 from 196 replies.



Attendees were quite satisfied with the venue despite some problems with the entrance. The average is 5.1.

Some felt the conference was too short. We would have loved to have held a three-day conference. However, it is hard for people to be away from work for even two days.

Apart from the speakers, other aspects attendees felt compelled to highlight in what they most enjoyed about the conference included:

- the opportunity to hear about – and then hear from – Amandine X, a singer-songwriter with PANS, who performed at the end of day one.
- visiting the exhibition that featured the artwork and written work produced by both children with PANS and their siblings. *Note: These works were cultivated from parents all over the world.*

The purpose of highlighting Amandine’s story and talent, as well as organizing the exhibition, was to strike a very personal and compelling tone that would remind attendees the reason the conference was organized. – Because patients and families are suffering from this devastating illness. It was imperative to us, as a parent/patient organization, that we kept that first and foremost in the minds of those attending. We were determined to ensure that PANS is not only looked upon as a “scientific matter” or “an interesting and difficult group of patients”, but as individuals.

The panel discussion, which was at the end of day two, was also mentioned as valuable by some parents and professionals. However, we believe there is an underrepresentation in the number of comments received about this component of the conference. We noticed that many delegates had already filled out their evaluations before the panel discussion was held.

Our concern was that we may have had fewer attendees with a longer conference. We will, however, take this into consideration for any future conferences. One solution could be to offer an optional third day.

One common criticism (around 15 attendees in total) was that time was not allotted for taking questions after each presentation. This is a difficult issue which we gave considerable thought. Instead of making time for questions after each speaker, we chose to instead gather questions for a panel discussion. It is our experience that people don't always phrase their questions succinctly, which results in very few questions being able to be asked. The at-

tendees may also benefit from hearing the same question answered by more than one expert to benefit from a more comprehensive response.

In the end, we were very much concerned about our ability to adhere to our conference schedule. Opening up to questions after each and every presentation could have affected our ability to stay punctual. Indeed, our ability to stay on schedule throughout both days of the conference was appreciated and remarked on by conference participants. Still for future events, we can consider having more and shorter Q&A panels.



Final Notes

This note regards our goal to include perspective from the individuals and the families affected by PANS. While several delegates (a mix of professionals and parents) specifically mentioned enjoying the mix of perspectives, a couple of medical professionals stated that it was very difficult to mix with parents and patients at a conference. This came in response to the question, "what, if anything, they disliked?" We found this a bit amusing, yet sad. If they chose to participate in an event organized by a parent-/patient organization, you would think they would have expected and been prepared for this mix. We are convinced it is important and beneficial for medical pro-

professionals to interact and learn together with parents and patients. In fact, those comments made us more aware and committed to how important and worthwhile this is. Perhaps it was uncomfortable because it is too uncommon. Meaning, some medical professionals have no experience with this level of interaction.

Having said this, we do know that several of the speakers, as well as attending health care professionals, chose to hang out and interact with parents during breaks and/or in the evenings. We also talked to many medical professionals and researchers during the conference who really appreciated the mix of perspectives.

"This is the first conference I have been to by an organization run by parents. It has provided invaluable insights for me. I want to say a massive thank you to the parents and children that have facilitated my learning."

(Child Psychiatrist)

"The three strengths of the conference were: The variety of expert perspectives. The more evidence based the better. Incorporating parent and patient presentations, and art."

(Health Care Professional)

Thank you, brave parents!
(Pediatrician)