



2016 Post Meeting Report

Prepared by Jamie Harvey, ICOSEP Chief Executive Director

Co-Founder, The MAGIC Foundation

It is with sincere appreciation of the global support by Novo Nordisk as the Platinum Level donor, and Ipsen as the Silver Level donor for making this meeting possible.



Materials and other artworks were provided all attendees on digital drives. Some presentations and materials will be loaded to the ICOSEP, private members only Facebook page. Please join this group to make certain you can always access documents.

For additional information, contact: jamie@magicfoundation.org

MEMBER ATTENDEES

Aleksandar Petrovski, ICOSEP President	PACT, Association of Parents of Children with Endocrinology Disorders of Macedonia, President Email: zdruzenierast@gmail.com
Aida Jazic	Association of GHD persons and persons with short stature "SA-RAST" President, Bosnia and Herzegovina Email: naida16f@bih.net.ba
Alina Toma	Atinge Curcubeul, President, Romania Email: alina.toma@atingecurcubeul.ro
Arlene Smyth	Turner Syndrome Support Society -United Kingdom Executive Officer Email: arlenesmyth@btconnect.com
Cindy Scurlock	Turner Syndrome Society, United States Executive Director tssus@turnersyndrome.org
Daniela Dippold	BSHV Federal Self Help Association, Germany Email: dippold.daniela@gmx.de
Denise Culin, ICOSEP Secretary	Turner Syndrome Global Alliance, USA Executive Director Email: dculin@tsgalliance.org
Diana Vitali	SOD Italia, President, Italy d_vitali@yahoo.com
Jamie Harvey, ICOSEP Executive Director	MAGIC Foundation, International Director. USA Email: jamie@magicfoundation.org
Jenny Child	Child Growth Foundation, Executive Dir., UK Email: jenny.child@childgrowthfoundation.org
Olga Davidovic	Horast, President, Serbia Email: kontakt@horast.org
Nick Child	Child Growth Foundation, President, UK nick.child@childgrowthfoundation.org
Mary Andrews	MAGIC Foundation, Chief Executive Officer, USA mandrews@magicfoundation.org
Radmila Kotic, MD	HORAST, Belgrade, Serbia rkotic@sbb.rs
Sachiko Kishimoto	Turner Support Society of Japan, President tshn53@khe.biglobe.ne.jp
Zsuzsanna Liebold, ICOSEP Ambassador	Germany zsuzsanna@leibolds.de

ICOSEP 2016 MEETING/AGENDA NOTES

Informal meet and Greet, Wednesday, 16 March 2016 18:00-20:00 /6:00-8:00 pm

Day 1: Thursday 17 March 2016 9:00-16:00 /4:00 pm

Welcome- President Petrovski and Jamie Harvey

Brief Self Introductions

TOPIC: 2015 Review and Follow up Comments of Last Year's Meeting Notes

PRESENTER: Arlene Smyth, Turner Syndrome Support Society -United Kingdom

2015 Follow Up

- 1) ICOSEP Facebook Group Address to be sent to all members for joining.
- 2) Stress using social media for all thank you opportunities to ICOSEP Sponsors and Growth Awareness Supporters
- 3) Asked if animated growth video could be unbranded for use by all groups and for use on ICOSEP YouTube channel.
- 4) Asked to download the 2015 and 2016 Meeting Notes to the ICOSEP website. Jamie Harvey to implement this after 2016 notes are approved.

TOPIC: Supporting Local Associations and Organizations through Education

PRESENTER: Doug Ordonez, Sr. Global Product Manager, Novo Nordisk

Notes: The average age of a child to start growth hormone is the 10 years old and has not significantly changed for 25 years. The primary cause is the pediatric "wait and see" protocols. Educating pediatricians has proven to reduce the average age of diagnosis to less than 6 years old and is a priority for all ICOSEP members. Novo Nordisk feels that it is a moral responsibility to assist efforts directed at earlier diagnosis to assist with the deterrence of possible long term health consequences from delayed diagnosis. They are actively taking steps with educational programs to encourage accurate and consistent growth evaluations and referrals for all children.

Follow Up:

- 1) Arlene and Alina want to be included in the educational efforts towards Pediatricians in their countries. Educational materials to assist with this are available through Doug only to ensure local governmental approvals are in place and permissions are granted for use of materials.
- 2) Resources available will be given to Jamie Harvey for listing on the ICOSEP website. [Referral check list, Growth Charts and Awareness materials. All will be unbranded or ICOSEP only branded.]
- 3) It was suggested to include excessive growth information too.

TOPIC: Evolution from Transactions to Partnerships Past. Present and Future

PRESENTER: Camilla Lauritzen, Global Head of R&D Communication and Patient Partnering / Strategic R&D, Novo Nordisk

Notes: Historically Patient Associations simply asked for financial support from drug companies for a variety of scattered building blocks. It was a solid way to assist the associations build a system to support affected patients. Today, we are expanding that system to build new systems which incorporate education and awareness as to the medical challenges of the specific disease conditions. This expansion should help generate a shift in the future

understanding of the plight of the patients and legitimacy of these varied and serious medical challenges. Partnering all those who support or have a vested interest in these medical issues encourages a much more successful result. Novo Nordisk has given ICOSEP and its members a promise to "listen" to our concerns, address them to assist us as much as possible, to share and communicate with transparency.

Lessons learned from other partnerships such as Eupati.org who systematically engaged Research and Development as well as patient advocate association leaders across disease areas. Networking resources encourages local as well as international coalition leaders insight as to what is going on per country and how to best access resources across platforms. Why spend time building a system when there are information systems already available and free for us to use which have a good record of success.

Several country leaders requested assistance on how to obtain assistance in their countries to facilitate the development of a country by country resource networking system.

Follow Up: Correct ICOSEP Facebook page to allow for "joins".

TOPIC: Successful Strategies for Soliciting Volunteers

PRESENTER: Cindy Scurlock, Turner Syndrome Society, USA

Notes: Begin to get volunteers by asking family and friends to help you. As parents contact you, have something very specific which they can manage easily and feel like they are an important part of the "team". Encourage volunteers of ALL ages. Children love to participate and teenagers can be great social media help.

Follow Up: Cindy is going to create a generic template of the "ask" for volunteers and share with members on the ICOSEP Members Facebook page.

TOPIC: Working Successfully with Local Governments

PRESENTER: President Aleksandar Petrovski, PACT Macedonia

Notes:

1. It is important to be well prepared before any meetings or conversations with government officials.
2. All decisions must be well communicated and agreed upon by local patient advocate member leaders.
3. Document all activities thoroughly and clearly.
4. Only share information among private Facebook groups.
5. Determine who are the best possible governmental representatives to help you and then focus on them. Build a team of supporters from local hospitals, drug agencies, ministries, universities, health care insurance funds and departments of health.
6. Establish relationships with all groups and maintain communications with each of them. Include your good network associates in your press functions so they develop an "image" of being a good supporter of your projects.
7. Recognize everyone for their dedication and involvement!
8. Always invite them to Growth Awareness activities and get pictures for the media. Post everything to public social media and websites.
9. Collaborate with as many local patient associations as possible. Encourage them to join ICOSEP.
10. "Be brave...speak louder...ask for the rights of the children and the patients...use any possibility."

TOPIC: Fundraising Ideas

PRESENTER: Sachiko Kishimoto, Turner Support Society of Japan

Notes: Ask!

1. Ask for donations from support organizations
2. Ask for donations on your websites for a specific project
3. Ask for donations for an annual gift
4. Ask for donations from product companies, drug, syringes and all products
5. Submit submissions for National grants

Make Fund-raising project enjoyable and sustainable.

1. Local community projects and neighborhood associations donate to charities.
2. Use "sympathy" donation requests.
3. Be specific to the area of your greatest need. Decide the donation method (online or other way) and make it easy to donate.
4. Include children in all projects!
5. Recognize donations in newsletters etc.
6. Paypal is a good location that is easy and fast to set up to begin accepting money.

General Discussion on areas where newer groups need guidance. Mentorship opportunities joined Jamie Harvey with the German groups, and Bosnia leaders.

Day 2: 18 March 2016

TOPIC: The Value of Social Media

PRESENTER: Arlene Smyth, Turner Syndrome Support Society -United Kingdom

Notes: Facebook

- Groups work better with "shares"
- Consider adding the work "official" at the end of a group name to differentiate it as a "real" professional group.
- Local chapters use "local friendship groups" and are a part of the larger group and all swap shares. For example one local group could be specific for child bragging or success stories of my TS girl.
- Only Pin posts that are most important
- Posts can be scheduled in advance using a service such as HootSuite
- Boost or sponsors posts/adds and choose your audience to reach outside your group.

Twitter

- Try to encourage a celebrity of any status to become a follower. They don't have to endorse it, just follow you because their many followers will see it and you will get good exposure.
- Can also be set up in advance via HootSuite

YouTube

- "Helped alot" with exposure
- Consider using video on your channel
- Encourage members to think about posting a personal story which you can either link to or host (as appropriate).

LinkedIn

- Build Linked In Pages for all groups and events

Growth Awareness Campaign, has seen an increase in interest and shares ranging from 670%- 1047% increase for the online event. Use a service like Hootsuite (or a similar free preset program) to set up posts weeks ahead of the campaign so that you can handle the work of the week as it comes in instead of having to post and handle the new work. Arlene preset more than 250 tweets for Growth Awareness 2015 which pointed to her website and Facebook groups.

TOPIC: Networking, The Value and Importance

PRESENTER: Denise Culin, Turner Syndrome Global Alliance, USA

Notes: Denise provided 2 excellent supplemental documents in addition to her very important presentation. All 3 documents in addition to all the presentations will be loaded to the ICOSEP Facebook group soon. Please download or review them from that area.

- Networking is the key to all success.
- Build a core group of 12-18 people, ask for help, be open and honest
- Make a good first impression when meeting new people. If they give you a business card, write something about them on the back of their card to help you remember details of meeting them.
- Always have extra business cards, and ask people questions. Put more emphasis on listening rather than speaking. You will learn more.
- Prepare a list of 5 questions you can use to initiate conversations.
- Get involved in your community to meet others who may be able to help you.

[Note: this is a very important topic for success. Make certain to download the documents to this topic.]

TOPIC: International Growth Awareness Week 2016

PRESENTER: Jamie Harvey, Executive Director, ICOSEP

Notes: Summary of the 2015 International Children's Growth Awareness Campaign included but were not limited to the following samples:

- Participating Members organizations has grown from 31 to 92 in only 3 years which is reflective of a large interest in this global initiative

- Novo Nordisk played a vital role on a global level to help all of us with our dream of this campaign. They supported posters, buttons, artwork and many activities. We could not have made changes in the lives of so many children without their support.

The Child Growth Foundation

Sent out more than 2,000 emails

Posted messages on their website and social media platforms

Results: More than 7,554 people learned about growth that day!

- The Turner Syndrome Society
Facebook messages went from 326 to 8,206
- The Turner Syndrome Global Alliance
Facebook reach increased by 792%
Sent emails to 500+ state health department offices
- The MAGIC Foundation

Facebook reach exceeded 54,000 (+795%) for September 15th alone
Messaged Profile Pictures were changed to match Growth Awareness (+83%)
Messaged Banner Pictures were shared (+71%)
Large webinar with school nurses was conducted.
- Many counties shared the Growth Awareness message with numerous projects.

The total international reach of this program has expanded as follows:

2012	The message reached and was responded to from people in 17 Countries
2013	30+ countries
2014	60+ countries
2015	147+ countries

Full presentations with details for the 2016 campaign was distributed to members via a digital drive. Information is sorted by geographic region and resources. For members, who were not able to attend the meeting, email jamie@magicfoundation.org for the report.

Follow Up: After reviewing the materials it was noted that the photograph of the children used in the examples is not suitable for Japan or Romania. Representatives from Japan will search for photography which can be substituted. Alina will seek a similar photograph for appropriate use in Romania.

Further discussion on this artwork is needed by all members.

Action Items

- Send your artwork to Jamie by Aug 1
- Send pictures of growth events during the year to Jamie
- Aida will contact Jamie when website, Facebook and logo is ready
- Help Romania with growth chart & reimbursement for standard deviation (SD not accurate in Romania)
- Submit Child Growth Awareness Day (Sept 20) to WHO or UN to recognize as national day of awareness
- Submit agenda items for 2017 meeting

TOPIC: **Patients Bill of Rights**

PRESENTER: Mary Andrews, The MAGIC Foundation, USA

Notes: ICOSEP should build a Patient's Bill of Rights which was changed to be titled-
Declaration of Patients Rights
Consensus of ICOSEP

A child's growth is not merely about height, but is about a lifetime of health. We recognize the importance of annually measuring and plotting of a child's growth throughout childhood to enable early diagnosis and access to the most current treatments available for children. Therefore, as a global coalition of organizations, associations, medical professionals and other valuable supporters of all children worldwide, **we declare:**

- All children have the right to grow to their full potential intellectually and physically.
- Factors negatively affecting a child's health and growth should be identified and addressed as early in development as possible.

Sample ideas of statements we may choose to include in this document are listed below. Members will be sent email reminders so that they can write their ideas as to good statements to include in this document. Following responses from all members, we will begin a process to build the statement and finalize it for International Children's Growth Awareness Week press work this year.

ICOSEP Business 2016

International Growth Awareness

The issue was raised by Macedonia that not having a fixed date is a challenge in their country as their local government is less likely to give official recognition to a "moving" date (e.g. third week in September). Italy, Romania and Germany also voiced it would be easier in their countries if there could be a set date. After consultation of UN calendar to avoid any conflict (which could be a negative future recognition by UN) September 20th was voted and agreed to. However, it was stressed to continue using the week around the 20th for activities. It was also agreed to still do major on-line "push" on the closest Tuesday prior to the 20th as lead up to event.

ICOSEP Board

The President asked for nominations for future president and officers. This raised question as to what are the list of directors/board and description of their responsibilities.

This led to discussion on how structured to make organization. Group voted to keep the design of ICOSEP operations more informal as of now, and revisit in future.

Aleksandar was voted to remain president and Denise was elected the official secretary. Thank you!

Jamie Harvey was given the title as Chief Executive Director of ICOSEP.

ICOSEP meeting 2017

Mary Andrews volunteered to coordinate meeting location for 2017.

Locations to investigate: 1) Munich/Berlin/Frankfurt, Germany 2) Bratislava, Slovakia 3) Bucharest, Romania 4) Copenhagen, Denmark 5) Rome, Italy 6) Prague, CR

Regarding date, it was asked of group if they preferred Thursday/ Friday or Friday/Saturday. Group voted to keep meeting on Thursday/Friday/ Saturday. March 10th and 11th 2017 agreed for date of next year meeting.

Future topics

- Topic was raised on need to have discussion for funding and how to handle funds for ICOSEP vs funds for individual organizations.
- Growth of group is anticipated for 3 to 5 members a year
- It was requested for next years meeting to provide a list of each attendee, a photo and a brief description of their organization including their focus. This list will be distributed prior to the arrival at the meeting so that new members can easily recognize people in the group.
- Topic was brought up about “re-branding” the term “shots” or “injections” (previously discussed last year. US did survey of possible other terms.

Growing potion

Medicine

Injection

Poke

magic medicine

Grow juice

Growing magic

Pinch

Power pen

Superhero serum

Super elixir

Needle juice

Butt medicine

Big girl meds

Sugar shot

Magic Juice

- It was suggested to use list/translations and do internal survey with members of the individual organizations to pick top names.
- More details were asked about the roles of the Ambassadors. This role is open to volunteers from different countries who can act as an interpreter/liason to the point person of the local patient organization back to ICOSEP. They require strong English language skills (written and spoken).

Follow-up

Jamie will:

1. Send out the minutes of this meeting
2. Make presentations available accessible within the private ICOSEP members Facebook page
3. Send an email request for agenda items for next year and
4. Begin the final process of communications with all member to get the designs and text of artwork corrected and tested for the 2016 Growth Awareness Campaign completed.
5. Establish an ICOSEP YouTube Channel for everyone to begin sharing links to their videos.

Meeting Concluded: Friday, March 18, 2016 15:30.