

## **ICOSEP MEETING**

March 10 – 11, 2017

Meeting Summary Provided by Denise Culin, Secretary

9:00 a.m.

Jamie – Welcome/Introduction

**Aleksander** – 5<sup>th</sup> annual meeting

Review the past few years of ICOSEP – 2<sup>nd</sup> year - ICOSEP small group to bring patients, family, and professionals together. Improve timely diagnosis

4<sup>th</sup> meeting – Lisbon – small group grows, more participants,

Here from all over to learn from each other and join efforts and energy to help children all around the world, better tomorrow for everyone.

Caring for health of our children we look out for our future generation and contribute to our future.

Begin the meeting and wish success.

**Jamie** - Individual introductions

Vote to accept last year's minute – unanimous to accept without changes

**Arlene** – Membership of Organizations – Some say the best type of membership is a paid membership. People value more if they must pay for it. Need to give members something that can't get without paying.

Doctors give a paper with info about TSSS and membership benefits

Benefits: 1) Part of a personal support group, 2) receive updated, accurate info 3) networking, make relationships with other families 3) access to medical advisors 4) access to conferences

Start with free information available to all but people need to support and give back. Reason join is to be part of something, like the info, friends, and access to specialist and taking part of research and changing the future.

TSSS – 30 £ year or £2.50 a month with 800 members. Annual conference is member only – for data protection b/c members share personal stories and need to be able to reach them in case of inaccurate info or other reasons.

To increase memberships, use a pay it forward philosophy – educate on what their money does ie: research, educate doctors, literature, etc. 2) Raise awareness in medical universities with physicians. Make sure doctors know you exist to refer families including subspecialties.

**Jamie – Social Media** – becomes problem when medical opinions are being given. If doing FB should announce you are not responsible for info or have someone moderate if medical info is being posted to interrupt and correct or direct to specialist. Guide the people to resource page.

To keep members long term – suggest to keep personal relationships with others.

Contact local societies about getting recognition on their website, newsletter, social media, etc. ie: ESPE, Endo Society

GAD – in Europe (GAW in US) – ask for everyone to focus on Tuesday and Wednesday. Hit social media hard on Tuesday 19<sup>th</sup> and again on Wednesday 20<sup>th</sup>.

Manual includes general information on how to get involved and ways to put out information. In most areas FB and Twitter. Try to get celebrities involved. Use Pinterest and YouTube. In Sept MAGIC and ICOSEP have a side by side booth at Endo Meet...will have video to get physicians to be recorded in their language to state the importance of children's growth. Once finished you can add to personal group websites and FB. If you have physician at the meeting, ask them to stop and participate in the video. The joint endo meet is DC Sept 13-17. Ask each member to get societies of each country to endorse children's growth awareness so it can be advertised at the meetings. Have them email their endorsement to Jamie. The countries who endorse will be recognized in the booth at the meeting.

Materials include pictures, press releases, tweets, artwork, etc. Artwork is included on the USB. Provides a branded look throughout all medias. Growth awareness logo is available to everyone for everything.

Suggestion – tape info about GAD to back windshield. Can cut out ribbons and have people wear on shirt for GAD.

Review calendar – Can use HootSuite to schedule everything in advance. Pay attention to Sept 19 and the suggested schedule to introduce on social media. Has been designed to build up to the GA day event. Try to get celebrity to retweet or share FB for better recognition. In general, ask people to share. We aren't rich or famous, just want to help children...please share our message. Equate growth to health in your message. Use resources like teens.

**Radmila** – media (TV) awareness last year, need to raise awareness that growth equals health to doctors and parents. That was main goal – TV, pediatric congress, children's school (they measure children every three months) so gave them a growth chart to alert parents if there is a problem in growth, gave statometers to schools and visited schools to show how to measure. Educated on how to react when there isn't typical growth. Program caused a double of endo patients from previous year. Had growth program and measurements at the mall.

Need to educate parents on the importance of measuring child. Teach lack of height has an impact on health.

Girls are treated differently than boys as far as when doctors want to start GH. Also, people don't understand that GH is ok to use. Doctors need to understand it isn't just cosmetic especially if patient isn't GH deficient.

Suggest to measure three times and take average versus a single measure especially for small child. If measuring laying down (length) use the 0-36 chart and if standing (height) use 2-18 chart.

Doug will send the GA video sketch file to Jamie to put on YouTube. Suggest to include this info as tools on the ICOSEP website for other groups to have access.

When a family receives a late diagnosis, ask family to go back to physician and provide information so they won't fail another child.

Use local media to expose your organization for GA.

Ask other organizations ie: Rare Disease, thyroid association, etc. to participate in the GA campaign.

Challenge men to pay attention to daughter's growth. A potential video taking a 10 yr. old child of average age to attempt to do everyday tasks to show importance of using GH.

### **Past experiences, successes, processes**

Nick – greatest response from twitter and FB.

Radmila – strength, her presence on TV.

Agree we need to work with pediatricians to better educate.

Jamie – need to focus on adults after they come off GH.

Connect adults and pediatric care to provide care for all patients. Transition from 16-21 in UK. Need to determine how to get adult GH care after they have achieved final height even if not GH deficient. Need research to prove the need. Transition program in the US makes it difficult to continue adequate adult care. Geography (kids going to college) makes it difficult as well as having adult professionals.

Compare the total number of growth disorders worldwide to a comparable well known disease (like Rare Disease is more common than Heart Disease).

Jamie will take statistics and give to each country so they can compare to incidence of other well-known issues in their country.

Roma – as medical student will talk to friends about GH deficiency and make it more informal than medical knowledge.

Jamie – Use testimonial video on YouTube to your associations site.

Rafe – for RDD go to clinicians in clinics to provide information. Emphasize it is the day for them to celebrate. Providing awareness. Include growth screening, educational coloring books, make it a fun day.

Need to get out of clinics and target the public, the schools, preschools, etc. to bring attention.

Aleksandar – awareness done year round, uses other disease days to promote growth (ie: leukemia, etc.) Kids were screened on main square and paraded with growth t-shirts, famous pop-singer did measurements, motivate kids to come by giving CD from pop singer.

Use other ideas besides social media to get the word out. Invite media to attend. Make sure you both have the same agenda. Use reporters you know so they don't exploit you to make money. Make sure they won't sensationalize it. Live interviews give you more content control.

Jamie provided list of tidbits of information

- Social media is important, ask local hospital to publicize
- As advocate, be sincere of what you are doing

### **FUNDRAISING – MARY**

Reviewed ideas from MAGIC. Even if it has low potential of income is worth because will have multiple people do the fundraiser ie: garage sale so it adds up.

Fun Runs, garage sale, restaurants give back, poker run, special events (golf tournaments), company matching gifts, Amazon, recipient for casual clothes day, Legacy (in honor of), Just Giving, have members participate by holding their own fund raisers, involve local pharma to participate in your event (like a marathon), some companies have a service day and may volunteer to work, request funds from different organizations (like backpack or toy makers), recurring donations, membership, ask your members and follow up with a thank you.

### **ROLEPLAYING MEDIA INTERVIEWS**

Be prepared to answer negative questions ie: why does your daughter need to be tall, is the cost of GH worth the growth. Find someone within your membership who has family or personal connection to media for personal relationship.

Look people in the eye when speaking.

Prepare ahead of time for potential questions.

Look for magazine that may offer a list of organizations for specific disorders.

Radio is free and is often live. Is an easy media to start with because it is only sound, don't need to be concerned about appearances. Most have Publics Service Announcement spots available like for a local event.

Does anyone know board members of ESPE to see if ICOSEP can get a working group on their agenda?

On a closed FB group the public can see who the members are though they can't see the posts.

Every time FB does an update your privacy settings are wiped out.

Groups in S. America, Russia, maybe China, Pakistan, Iran, Africa (Uganda, Republic of Congo), medical societies asking for updates, highest hit on website is association page, dealing with issues of trying to get medicine to patients, solutions to get people access.

### **Saturday, MARCH 11**

Thank you to all our donors and to Jamie for the work put into ICOSEP.

**SACHIKO Please send COPY OF PRESENTATION for the records. Thank you!**

### **Kondo Kinichi – SRS**

Presents on participating in IGAD. Founder SRS Network.

ICGAD – PR activities on the web, SNS, email and posted pictures on Instagram. Join GA committee (as director) to work with Sachiko.

Kinichi included some information about RSS (SRS).

SRS network 23 parents and 2 patients. Participate in 3 activities – 1) participate in J-RARE (online registry) 2) conduct workshop 3) awareness activities like IGAD and Rare Disease Day

Shun Emoto – SRS Network – J-RARE

Presents about ASRID – Advocacy Service for Rare and Intractable Diseases – Including mission for groups to work together

Activities – medical guidelines, joined with other international orgs for conferences, have Rare Disease Day, established online patient registry for rare disease that includes SRS. Recruiting patients one of biggest problem to complete research.

QOL (quality of life) Research in SRS – studied from patient point of view (ie: foot malformation info not provided in recommendations so included in the registry to study foot malformation).

Suggestions for others who are considering approaching their medical societies or governments to get GAD recognized – work together (bring in other growth groups). Japan made a committee for Growth Awareness Day.

One possible way to get GAD recognized through government is to bring several groups together for strength, maybe have a celebration for a positive expression, and for individual countries find someone local who has become recognized and ask how they accomplished this.

**Jamie** – will provide complete email list and picture to all attends.

**Jamie** - Presented Consensus Declaration Statement and Declaration of Growth Affected Children's Rights – Open Discussion

Remove “of behavior”

Basic expectations could be too broad – because each person's expectations are different.

Change from question to statement Patient's Rights. Reorder with Growth is important first, Declaration then Patient's Rights.

Final suggestion from Italy was to take the Declaration from the growth organization to recognize as our declaration.

Aleksander will take recommendations, adjust, then send to the board for approval.

**ESPE Meeting DC** – ICOSEP will share a table and have a video recording asking for doctor's support. Looking for volunteers. Anyone who wants to join need to commit by June 1.

**2018 Meeting Date and Location** – vote for Warsaw and Madrid. Madrid was first choice. Alek will look at both to make final decision. Will consider Prague.

April 1 and 8 of April for Easter, members will send Endo meetings for April and May. Holidays fall two weeks before and after Easter. Cost should be first consideration for dates. Jamie will look at costs versus dates before a final date is determined.

Board – Should expand the board? Arlene/Nick – board should be engaged and have more contact. Board should make decision for future meeting dates and locations.

Suggest that the board remains the same. Soon after the meeting we will have a conference call to discuss the structure and responsibilities of the board. Included will be the board's responsibility to make decisions versus putting before the whole group. The board will meet face to face prior to the start of GA meeting.

Send our awareness information to Jamie to put on ICOSEP to advertise for us. She can add to FB and website.

Develop a script and have each person speak in their language so it tells the whole story of ICOSEP. This should be coordinated to produce at next year's meeting.

Need someone to collect info for newsletter, send out email reminders to collect info, then send to Jamie to put in newsletter format. Aida Jasic will coordinate this.

Next year, Jamie will email the documents and each person will print their own documents for the meeting.

Use WeTransfer, DropBox, or the Cloud for the art files rather than sending it on an USB. Jamie will make it available in both formats.

Aleksander suggests using visual presentations more, easier to understand.

NICK – CGF - SRS – 2015 large meeting of experts. Generated a consensus on how condition dx and how managed and treated. Starting to push the awareness of the document to educate all endocrinologists. SRS Global Alliance – patient support organization with key medical specialists. Mission to standardize information. Spreading throughout the world to provide information.

Dianna – Septo Optic Dysplasia(SOD) is a mid-line brain defect. Very rare – trying to build international network. Ask each person here to connect them with Dianna. Email Diana Vitale (also called optic nerve hypoplasia).

Jamie – thanked everyone for attending

Aleksander – Thank you everyone, Jamie for organizing the meeting. Together globally and locally we can do a lot. In his country ICOSEP helped to overcome a dilemma. Highlight the motto: Taking care of our children, we are taking care of the future. ICOSEP should be a good example for other organizations. Safe travels.

Meeting ended at 11:45am.