



**Annual Members Meeting
Vienna, Austria
Imperial Riding School Renaissance Vienna Hotel
May 2-4, 2019**

Friday

ICOSEP General Meeting

8:00 a.m. – 8:30 a.m.

Welcome and Introductions

Hosted by: Zsuzsanna Liepold, ICOSEP Director of Ambassadors

8:30 a.m.-9:00 a.m.

General review of 2019 Growth Awareness Campaign and Materials

Introduction and Goal Setting for your Organization

Presented by: Jamie Harvey, Chief Executive Officer, ICOSEP

[Distribution of Notebook] Topics will include your Goals for GAD (throughout the year), Media and Social Media Goals, Challenges Faced in Previous Years, and SWOT (Strengths, Weaknesses, Opportunities, and Threats of reaching your goals).

9:00 a.m. – 10:00 a.m.

General Session: **Sharing your Story with the Media**

Presented by Mary Andrews, CEO of The MAGIC Foundation

General statement overview: What types of stories are appealing to news representatives? Do you feel overwhelmed by interviews? During this presentation, you will learn how to keep your interesting story simple for media coverage. We will also give tips on how to keep the interview under your control. By the end of this session, you will have the understanding of how to write your story and present it to media representatives in your area.

***The notebook has a page for Media Goals and we will work together later in the day to share experiences and discuss options which may work for your organization.

10:00 a.m. – 10:15 a.m. Break

10:15 a.m. – 11:00 a.m.

General Session Discussion: **The Importance of Social Media for the Independent Patient Advocate**

Presented by Cinzia Sacchetti

1. Make it easy 2. Time management 3. Routine 4. Evaluate results

Learn from others, and share ways you have found successful for improving your social media and web presence for patient organizations. Discuss the process of building a website, managing SEO, and maintaining social media presence. Get useful advice and tips no matter what your level of social media skill is. You'll also learn useful business development strategies for starting and growing your organization in the current technological world, such as building a business plan, performing market research, and identifying the appropriate demographic for your organization. Find out how you can grow and create a successful group, while building awareness for your organization.

11:00 a.m. – Noon

General Session: **The Value of Networking**

Presented by Diana Vitali, President SOD Italia

When dealing with unique medical issues it is often difficult to receive the attention your child requires. There can be mountains of problems and challenges to obtaining medical care because no one knows what category to put your problems in. President Vitali has experienced this challenge personally and will share her experience in how networking can benefit your child's health care. Sometimes, the person or area that you expected the least help from...can be the most effective.

Noon- 1:00 p.m. Lunch

1:00 p.m.-2:00 p.m.

Breakout Groups: **Goal Setting**

In this session, we will divide into 3 groups to share Growth Awareness Day experiences. Each group will share their past good experiences and challenges. Here, the discussion will be to help each other understand and develop organizational and GAD goals outlined during the discussion at 8:30.

(Please be prepared with any examples and materials you have used to share with your group.)

2:00 p.m. – 3:00 p.m.

Summary Presentations from 1:00 Breakout Groups and Discussion

3:00 p.m. -3:15 p.m. Break

3:15 p.m. – 5:00 p.m.

General Session Questions and Answers: **Countries have Different Methods**

Pharma Panel: Inviting one representative from each company attending to participate on this panel.

Each country has unique laws regarding patient organizations. In this session, we will have a panel available to answer challenges you have experienced in your area. Topics may include information about private healthcare, universal healthcare (country wide) and how it affects the patients. At the end of this session, each member will be able to create different methods to achieve their goals with the awareness campaign. Please give this topic some thought prior to the meeting and be prepared for questions.

Elaborate on topics concerning diseases that are treated with GH and understand how the prescription of this therapy is regulated in various countries.

If there are competent bodies and which ones are how to guarantee the care of all children even with diseases not recognized by these laws. if this therapy is given free by the national health service, or if families have to pay and how much.

Saturday

8:00 Arrival Coffee

8:30-9:15 Medical Updates (per request groups want to know if there are any medical advances for growth children)

General Discussion/ Questions and Answers from the Group/ Inviting Medical Liason's from Pharma to participate

9:15-10:00 2018 Growth Awareness Day Summary Discussion

Each attending group will share what they did for Growth Awareness and the results. Please send materials you want copied and presented to jamie@icosep.org NO LATER than March 2019. Failure to send material by that date will require you to make copies and bring them to the meeting.

10:00-10:15 Coffee and Break

10:15-11:00 The Healthcare Industry is not a Proxy for the Patient Voice

Your Voice as a Patient Advocate Leader is Powerful

11:00-noon Any follow up discussions which were not previously completed or suggestions for the upcoming 2019 Growth Awareness Day initiative. How can ICOSEP best help?