

CYE Conference 2019 - Minutes

27 - 28 of September, Milan

Countries and delegates present (in alphabetical order of countries):

Delegate	Coeliac Society	Country
Klara Laskova	Spolecnost pro bezlepkovou dietu	Czech Republic
Matej Biskup	Celiacs' Association of Czech Republic	Czech Republic
Samuel Rubín	Celiacs' Association of Czech Republic	Czech Republic
Sigrit Keerd	Eesti Tsöliaakia Selts	Estonia
Marja Jeskanen	Finnish Coeliac Society/Finnish Youth Coeliacs	Finland
Marvin Mueller	Deutsche Zöliakie-Gesellschaft e.V.	Germany
Steffi Ischner	Deutsche Zöliakie-Gesellschaft e.V.	Germany
Larissa Nitz	Deutsche Zöliakie-Gesellschaft e.V.	Germany
Luana Giberti	Associazione Italiana Celiachia	Italy
Luca Pocher	Associazione Italiana Celiachia	Italy
Marco Calzi	Associazione Italiana Celiachia	Italy
Marco Calzi	Associazione Italiana Celiachia	Italy
Liz Dahm	Association Luxembourgeoise des Intolérants au Gluten	Luxembourg
James Grima	Coeliac Association Malta / CYE	Malta
Marissa Seimons	Coeliactive	Netherlands
Dana Limburg	Coeliactive	Netherlands
Beatriz Garre Picazos	FACE Joven / CYE	Spain
María van der Hofstadt Rovira	FACE Joven	Spain
Eduard Colomer Castello	SMAP - Celiacs de Catalunya / CYE	Spain (Catalunya)
Rebecca Neuhold	IG Zöliakie der Deutschen Schweiz	Switzerland
Moa Borg Renlund	SCUF	Sweden
Magdalena Lundqvist	SCUF	Sweden

Marcus Svensson	SCUF	Sweden
Emma Vengemyr	SCUF	Sweden

Friday, 27th September

Opening of the conference

Introduction by James Grima, General Coordinator. Mentions main projects of the CYE: Summer Camp, Beat the Wheat, Travel Net and other annual projects. The importance of the summer camps to build social relationships and of Beat the Wheat, which was turned into a blog.

As part of the CYE introduction, James goes into a brief overview how the board works throughout the year with a budget of €7,000, that meets three to four times per year.

Group activity to get to know each other with an interview-like game. Round presentation of the delegates with fun facts.

Gluten Free Emoji Proposal

Discussion about gluten free emoji, which doesn't exist yet. James talks about a possible proposal. The proposal includes an emoji representing the crossed grain symbol.

Usually people use a combination of two emojis. Using a single symbol helps to have a direct association with coeliac disease and gluten free.

Problem of current emojis: same emoji used for wheat and rice on WhatsApp is a strong argument for a new emoji.

Deadline to make a proposal, March 2020. If accepted, we'll need to wait until 2022.

Approve the 2018 minutes

The CYE board presented the minutes of 2018 and asked all delegates to approve these minutes. All delegates unanimously approved the 2018 minutes.

The work of AO ECS - Christian Scerri and Izaskun Martin

Christian Scerri (Malta) from the AO ECS board talks about relationship between AO ECS and youth activities. Why should people join the AO ECS group? This is the main challenge. Confirms his support to the CYE.

Izaskun Martin (FACE) from the AO ECS board speech about AO ECS's activities. Difficulty of working together with so many different societies. Main objectives: improving coeliac rights and harmonising the projects we already have. Whilst also make sure that bigger associations help the smaller ones.

Short history of the AO ECS and CYE, from 1988 and 2001 to this Milan's conference.

Presentation of AO ECS's structure/framework. Based in Belgium, 40 member societies in Europe and other continents (USA, Israel, Jordan). Board meets during the year and visits events and scientific conferences.

ELS Project (Crossed grain trademark)

Updating the charta and standard. Not only quantity, but also quality. Fundamental role of the symbol to help coeliac people recognising gluten free products. Under the symbol you see the country who granted the license, the firm's code and the product's number. The logo is registered and cannot be used without permission. It is important to keep the situation under control and report any incorrect use.

Eating Out project

Harmonise the eating out projects of the different countries. In total more than 12,000 venues all over Europe. Problem of venues who would like to offer gluten free meals but don't have the right knowledge.

Scientific Advisory List (SAL): Monitoring technology to improve and create new cereals.

Further discussions

- CYE, the importance of the group
- Defending the rights of coeliacs before the governments. New aspect: gluten free vegan food
- Proposal: doing a gluten free trip advisor
- It is vital to improve the visibility of the AOECs and of the CYE

Travelling being coeliac - Eduard Colomer and Beatriz Garre

Eduard and Beatriz compare the different ways one can plan a gluten free trip. Main problem will remain eating out.

CYE's Facebook group is open to everyone and many people ask about tips. Objective: minimising fear of travelling with coeliac disease. Fight for gluten free options in restaurants.

CYE Travel Net: correcting mistakes.

Different situations: Europe is in a better situation than other non-European countries.

Beatriz shares her experience traveling around China. Very difficult situation there, not easy to find gluten free food. It's difficult to find people who speak English. Labelling is only in Chinese, so it's complicated to read ingredients.

Travel Net: taking it a step further - James Grima and Beatriz Garre

Beatriz and James introduce the project and the website's section.

Travel Net needs some updating.

Current structure: countries of AOECs/CYE travel details including:

- Native language information

- Where to buy gluten free food
- Gluten Free venues
- Local products

Potential ideas to help the projects grow:

- Linking data (Facebook group)
- Offline access (option of downloading information as a PDF)
- Information about countries without delegates
- Other information that can be added:
 - Information about specific regions (important for bigger countries)
 - Facebook groups and/or websites from the country when you can ask beginner questions
 - Links of specific venues
 - Possibility of a gluten free map of Europe
- Find ways to advertise Travel Net
- Problem: how to advertise Travel Net.

Good examples of how to improve the project can be seen at Coeliac UK's website - Eating out guide which includes local group venues recommendations.

Deadline to update Travel Net, end of 2019.

Website and Social media

Discussing ways to improve our presence on social media and how to create better content. Delegates watch videos created during the 2017 conference in Belgrade.

Improving our content (Instagram and Facebook):

- Videos (high quality)
- Regular content
- Competitions

Competition opportunities:

Christmas social media contest with Schär. Other good moments for a competition could be in May, after the Summer Camp or in February.

What kind of price/gadget/merchandise could we give to the competition's winner? CYE gadget or Summer Camp place (€300-400).

Campaign idea: Raising awareness

The delegates were divided into 4-people groups to create content: making a video.

Discussion about creating video content, delegates watch examples of videos. Watch video with interview by CYE delegates during the 2018 Budapest conference.

Delegates groups present their ideas to make their video:

- Group 1: speed interview with short answers with “I’m coeliac” in every language
- Group 2: supermarket scene, scene with doctor, a coeliac has to go either to a pizza or pasta place
- Group 3: interview coeliacs from AOECS
- Group 4: coeliac eating a croissant and then waking up finding out it was only a dream

Summarising the proposals and trying to plan how to combine them in a video.

Saturday, 27th September

CYE Board roles and responsibilities

James Grima opens the second day of CYE conference with a talk about the responsibilities of the CYE board. This is in preparation for next year's elections for a new CYE board.

The board and delegates discuss the responsibilities of the three roles:

- General Coordinator: coordinates the board; is the leader; connection with the AOECS
- Project Manager: contact with delegates, follows ongoing projects with the help of the delegates
- Financial Manager: handling of CYE's finances

The board's work throughout the year includes:

- Skype meetings
- 3 to 4 meetings in a European country per year
- Contact with Summer Camp organisers and Beat the Wheat team
- Work on the Annual Project

Plans for 2020:

- Ask AOECS for a budget increase for future CYE boards. The CYE budget, €7,000, has been the same since the beginning.
- Create a starter guide/starter pack for new delegates
- Try to involve the candidates in the 2020 projects
- Create a roadmap for the coming years

Proposals to improve CYE

The current structure has the 3 board members with defined roles, but there's no structure and responsibility for delegates. This can make it difficult for delegates to feel part of CYE.

One way to improve this is to create roles that delegates can be part of. Roles include:

- Social Media
- Travel Net
- Summer Camp
- Website

Another option to help CYE grow would be to be open to external contributors, not only to the CYE delegates. For example, try to get the Summer Camp participants involved.

Delegates were asked if they're interested in joining the working groups. There was a positive response, enabling the board to create not just roles but Working Groups for each role mentioned.

Introducing EPF and our potential representative

Ivana Losa, Italian delegate to the AO ECS, introduces Marco Greco, the president of the European Patient Forum. Marco Greco, introduces EPF to CYE and talks about how he created the first EPF youth group, with CYE being an inspiration to his work.

Fiona Greenhalgh (via Skype call)

Fiona, CYE's potential EPF representative, introduces herself to all delegates, her background and what she hopes to achieve through EPF as a coeliac youth representative.

Summer camp 2019: France - Nicolas Hauvel-Doxaran

Skype call with Nicolas, organiser of the 2019 CYE Summer Camp in Paris. He presents what they've done during the event and how they organised it.

Their main problem was the location, which had to be in Paris. A big challenge they faced was keeping the price as low as possible for participants. They managed to organise a summer camp full of activities for 50 participants in what would be considered as an expensive city.

Summer camp 2020: Italy

Summer camp 2020 organising team (Marco Calzi, Matteo Calzi, Luca Pocher, Luana Giberti) present a provisional plan of next year's Summer Camps.

The camp will be in Lignano Sabbiadoro (near Trieste) from the 26th July to the 4th of August.

Experiences from summer camp participants

Seven Italian participants of numerous CYE Summer Camps joined the conference to talk about their summer camp experiences - Clara Palmeri, Filippo Grassi, Francesca Civolani, Matteo Magnanini, Rita Magnanini, Debora Bonomi and Federica Celli.

They discussed how they found out about the Summer Camps, what kind of experiences they had and their favourite stories about it. They make their suggestions to future Summer Camp organisers. How this experience influenced their life and their approach to coeliac disease.

Summer Camp 2021

Unfortunately delegates at the conference could not vote for the 2021 Summer Camp since CYE did not receive any official candidatures. The board discussed why this event is so important and encouraged delegates to try and propose the idea of a summer camp to their associations.

As an alternative plan, the deadline for proposals for Summer Camp 2021 has been extended to December 2019.

Potential candidates may be Greece (hosting the Summer Camp in June or September) or Hungary.

Beat The Wheat - María van der Hofstadt

María discusses Beat the Wheat's transition from an online magazine to an online blog and how we can improve in keeping this project alive.

Delegates were asked to do a SWOT analysis of Beat the Wheat.

SWOT Analysis

Strengths	Weaknesses
<ul style="list-style-type: none"> - Variety of Subjects/Topics - Adapt Scientific Research in an easier format - All delegates involved with CYE can contribute - Regular throughout the year - A specific team working on BTW - Strong platform representing youth patients and AO ECS 	<ul style="list-style-type: none"> - Motivation for countries to provide content - Unknown to coeliacs worldwide - SEO - Update BTW page with categories - Sharing BTW's content
Opportunities	Threats
<ul style="list-style-type: none"> - Translate articles - Share content in national associations or youth group websites - Potential advertising or sponsored posts - New delegates are potential contributors to the project - Coeliac Disease will never disappear 	<ul style="list-style-type: none"> - Many popular blogs and influencers with the same type of content - Follow the current trend rather than the associations, youth groups or organisations - Content not regular enough

Discussion: Possibilities for Israel to start a youth group

Liat Kosovich, a member of the Israeli coeliac association and AO ECS representative, joined CYE to discuss her aims to create a youth group in Israel. Delegates discussed what type of activities and incentives they do in their countries which may help Liat to get young coeliacs involved in Israel.

The Three Little Pigs

Summarising the work of the CYE group during the conference with an exercise classifying the points under the houses of the three little pigs - Straw being the weakest, Wood as things to improve and Brick as CYE's strong points.

Straw House	Wooden House	Brick House
Motivation	Ongoing Projects	Welcoming Environment
Communication	Youth Groups networking	EPF
Annual Project		Summer Camps

CYE Presentation at the AO ECS General Assembly

The CYE board presented the 2018-2019 Annual Report to the AO ECS GA.