

CYE Conference 2020 - Minutes

2-3 of October (Online Conference)

Due to the COVID pandemic, the CYE Conference 2020 was held online. Apart from the delegates listed below a number of youth participants joined our Friday and Saturday sessions.

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

Delegate	Coeliac Society	Country
Samuel Rubín	Celiacs' Association of Czech Republic	Czech Republic
Marja Jeskanen	Finnish Coeliac Society/Finnish Youth Coeliacs	Finland
Steffi Ischner	Deutsche Zöliakie-Gesellschaft e.V.	Germany
Larissa Nitz	Deutsche Zöliakie-Gesellschaft e.V.	Germany
Dorottya Komlósi	Hungarian Coeliac Society	Hungary
Luana Giberti	Associazione Italiana Celiachia	Italy
Luca Pocher	Associazione Italiana Celiachia	Italy
James Grima	Coeliac Association Malta / CYE	Malta
Marissa Seimons	Coeliactive	Netherlands
Patrícia Lima	Associação Portuguesa de Celíacos	Portugal
Iulia Martinescu	ARIG, CeliYouth Romania	Romania
Beatriz Garre Picazos	FACE Joven / CYE	Spain
María van der Hofstadt Rovira	FACE Joven	Spain
Ana Prats	FACE Joven	Spain
Eduard Colomer Castello	SMAP - Celiacs de Catalunya / CYE	Spain (Catalunya)
Rebecca Neuhold	IG Zöliakie der Deutschen Schweiz	Switzerland

Friday, 2nd October

Four sessions open to Youth Participants and CYE Delegates.

Introduction to CYE

After a brief introduction of all delegates and youths that joined the call, an introduction to CYE was given by James Grima, General Coordinator. The introduction started off by an explanation how CYE relates to AO ECS and CYE's main purpose.

This was followed by a detailed overview of CYE's main projects: Beat the Wheat, Travel Net, Social Media and Summer Camps. The final part of the introduction was about how one can be part of CYE. Three ways were mentioned: CYE Delegate, a CYE Board member and as an External contributor. Helping CYE as an external contributor is still something that is being discussed. The hope is that other coeliacs (not just delegates) can contribute to CYE's work.

Status on Summer Camps and other projects

An update was given on the current status on CYE's main projects. Due to the pandemic, 2020 has been a difficult year for some of CYE's projects.

Summer Camps

CYE Summer Camps in 2020 and 2021 were planned to be held in Italy and Portugal respectively, COVID-19 impacted these plans. After a discussion with both organising teams, it was agreed for each Summer Camp to be moved by one year. Therefore, Italy will organise the Summer Camp in 2021 and Portugal in 2022.

A dedicated Facebook page was created for CYE Summer Camps with the aim to keep those interested up to date rather than creating a temporary Facebook page for that year's event.

Travel Net

Plans to extend Travel Net to non-European countries are still pending. Whilst going through some of the countries, it was clear the information on a number of countries is outdated. Participants from Cyprus and Romania offered to add their countries to the project.

Beat the Wheat

The project has been running since 2012, recently changed from an online magazine to an online blog. Unfortunately new articles have been lacking this year.

Social Media

Whilst travel related content was not used during 2020, CYE still managed to create some engaging posts. New content is always welcome, especially when social media can link to other CYE projects.

A participant suggested that CYE should explore using Twitter as well. Knowledge of Twitter may be a bit limited but it can be considered as a possibility.

Discussion on Working Groups

An introduction to CYE's Working Groups was provided explaining that their main purpose was to provide a better structure within CYE and hope it helps CYE Delegates to be able to focus on one contribution.

The discussion continued with describing the current Working Groups (Summer Camps, Travel Net, Beat the Wheat and Social Media) and what characteristics may be helpful to contribute in each group.

After the presentation, a number of improvements were mentioned such as having a dedicated person taking care of each Working Group and ways to improve communication with the CYE Board and the delegates. All of these points were to be discussed further on Saturday.

Future of CYE

A brief discussion on CYE in 2020 and what CYE can potentially focus on in the coming years.

CYE 2020

The current board ends its two-year term, a new board will be elected on Saturday for the 2020-2022 term. The current board has prepared a number of documents which they hope can help future CYE Board members and CYE Delegates be prepared how they can work and contribute.

Other points mentioned:

- Summer Camp updates: Italy in 2021, Portugal in 2022
- Improving communication between CYE and AOECs

CYE in the coming years

A potential new role can be created within CYE. This role would represent coeliacs in EPF's Youth Group. This is something that is still in its initial stages, a presentation by the EPF Youth Group on Saturday should provide us with more details.

Something that has been repeatedly mentioned in past conferences, try to improve on the communication between the CYE Board members and the delegates. Improving communication will help CYE grow and reach out to more coeliacs.

Saturday, 3rd October

Saturday was split into two parts, first part for all Youth Participants and Delegates. The second part was only for CYE Delegates.

Youth Participants and CYE Delegates sessions

Introduction to CYE

Having new CYE delegates and participants that did not join Friday's sessions, Saturday started with another brief introduction to CYE as well as a quick round up for everyone to introduce themselves.

CYE 2020 and the past years

A presentation summarising the Annual Report of 2020. COVID-19 had an impact on CYE's work especially the CYE Summer Camps. Whilst, it was a difficult year CYE had a number of positives:

- New CYE Delegates representing Portugal and Romania
- Improved communication between CYE and AO ECS
- Preparing CYE for the next years in the form of documents which will be discussed later in the day

Same as previous years, social media keeps helping CYE to engage with coeliacs online.

The CYE Board also shared some points of what was achieved during the past few years:

- The introduction of social media (Facebook and Instagram)
- Supporting CYE Summer Camps
- Bridging the gap between AO ECS and CYE
- Attracting new CYE delegates

Past delegates experiences

Two former CYE Delegates, Alessia Patuelli (Italy) and Christia Simillidou (Cyprus), joined us to share their experiences during their time with CYE. Both Alessia's and Christia's experiences showed how volunteering and contributing with others can help you grow in so many different ways.

Given that CYE brings together young coeliacs, there is something rather special in meeting people, in conferences or CYE Summer Camps, that share the same conditions as you. There's always a shared understanding. This helps everyone build stronger relationships.

Whilst working on projects, improving processes is important, the most important thing is to try and build a form of relationship with others. Making that step helps make the rest of CYE's work more enjoyable.

Delegates: Coeliac Disease in your country

Delegates were asked to share their experiences with coeliac disease in their countries. Whilst certain countries may have better awareness, one interesting factor that may affect the level of awareness is the type of diet a country has. For example, a country may be heavily based on flour whilst others are more inclined to use naturally gluten free ingredients.

The EPF Youth Group (European Patients' Forum Youth Group)

Two EPF Youth Group members joined us, Jana Popova and Anastasia Sofia Semaan, to give us an introduction to The EPF Youth Group. Their presentation focused on EPF and the EPF Youth Group, how can one get involved and STYPA: Summer Training for Young Patient Advocates.

It was noted that it can be a great opportunity for CYE delegates, as well as youths within Coeliac Youth Groups to attend such training as STYPA. It also offers to be a different experience to CYE as EPF brings together patients suffering from different conditions.

The Ultimate CYE Quiz

A fun way to relax from the morning presentations.

Ana Prats (CYE Delegate - Spain), prepared a quiz with a set of questions ranging from general knowledge to tricky CYE questions.

US perspective on CYE

Allie Scheiber from the US, who has been to a number of CYE Summer Camps, joined us to give us her perspective on CYE, her experiences in CYE Summer Camps and differences of how coeliac disease is perceived in the US and European countries. Allie also was happy to give us an insight on things you should do before travelling, especially when travelling to countries where awareness may be lacking or have a language barrier.

CYE Delegates Session

AOECS presentation

Katre Trofimov, an AOECS Board member, gave a short presentation on AOECS, its current projects and plans for AOECS' next Strategy Plans. She hopes that it will include CYE, which will help bring it closer to AOECS.

After Katre's presentation, we discussed the importance of the presence of coeliacs within AOECS. Whilst AOECS is an organisation dedicated to Coeliac Societies, prominent AOECS members may not be coeliacs themselves. This makes it more important for coeliacs, especially delegates from CYE, to contribute within AOECS. Being a voice in AOECS that suffers from coeliac disease on a daily basis can never be ignored.

New CYE Documents and Guidelines

During this year, the CYE Board prepared a number of documents and guidelines with the aim to help future CYE Board members and CYE Delegates.

These documents include:

- Guideline to select a CYE Delegate: Since CYE delegates change on a regular basis, the board felt to prepare a document to guide association/youth groups to find ideal candidates to be a CYE delegate.
- Suggestions for CYE board members: A set of suggestions to help CYE delegates interested in being part of the CYE Board.
- Starter pack for new CYE Delegates: A document to help new CYE delegates familiarise themselves with CYE, the projects and how can one contribute.

The purpose of these documents is not for them to be simply saved in a folder but to be used and shared with others when necessary. They can also be reviewed and updated from time to time.

A suggestion raised was to find a way to have these documents available on CYE's website. This can be done in a way where users request for access of files. Such a section can also extend to other documents that CYE delegates would like to share with CYE.

Working Groups: How to improve

In 2019, CYE decided to create Working Groups for each main project (Summer Camps, Travel Net, Beat the Wheat and Social Media). The aim was to help delegates find what they can contribute in as well as improve communication between the CYE Board and the delegates.

Whilst it was a step in the right direction, there's room for improvements. The main issues we had during 2019 were:

- Communication between the CYE Board and Working Groups could have been better
- Some Working Groups did not have a dedicated point of contact
- No structure for regular updates between the Working Groups and the CYE Board

In order to tackle these issues, the CYE Board suggested the following improvements:

- Have a dedicated Lead for each Working Group
- Set regular meetings between the Leads and the CYE Board
- Each Working Group set a set of goals for the year
- Other suggestions included setting up other groups: External Contributors and Past Delegates

Whilst discussing the Working Group a suggestion was raised for CYE to create a Communication or Secretary role. This role could facilitate follow-ups that may sometimes go unnoticed by the CYE Board or Delegates. It would also help the board members to focus on other work.

New CYE Board for 2020-2022

The two-year term of the current CYE Board has ended. Two board members, James Grima (Malta) and Beatriz Garre Picazos (Spain) were not able to contest for the new CYE Board due to its age restrictions. Therefore, two positions were vacant.

CYE had two candidates, Marissa Siemons (Netherlands) and Patrícia Lima (Portugal) who will take the roles of General Coordinator and Project Manager respectively. Eduard Colomer Castelló will remain as Financial Manager.

The CYE Board members for 2020-2022:

- General Coordinator: Marissa Siemons
- Project Manager: Patrícia Lima
- Financial Manager: Eduard Colomer Castelló

Presentation to AO ECS

James and Eduard joined AO ECS to present CYE's work in 2020 and also announced the new CYE Board for 2020-2022.