

EFCCA Youth Group



*Loekie for Rookie History Guide
A Guide to Our Activities and History*



Chayim Bell - Former EYG leader

In 2003, I attended my first European Youth Meeting (EYM) in Berlin. I didn't know what was expected from me, but I wanted to travel beyond my own country and see how young people lived with IBD in other countries. So much happened during my first conference that it overwhelmed me, and I didn't know what to do. At one point, I was afraid to say anything because everyone else seemed so much more capable of this work than me. Looking back at that experience, I now think that every idea we have is good, and worth sharing. We just need to find the right tools to get each idea started.

We invite everyone who attends the EYM to take an active role, and let us know what you think and want. If you feel that something in Europe or your country is missing, and could help young people with IBD, please speak up, so that we can take action together. At the EYM, you are a tool for your country - your country's national spokesperson. Everything that is happening in your national IBD association, and in your own country, can be shared with other people at the EYM - whether it's a successful project or activity, or something you need help with. Maybe there is someone at the EYM that has a similar problem or experience that can help you. Share your thoughts and activities. You never know, maybe we can all use it to help children and youngsters in a positive way.



This guide is a tool that the EYG has specially made for all the newcomers to our meeting, as I once was myself. In this guide, you can read how the EYM works and what EFCCA Youth Group (EYG) means. You can also find the names of the EYG leaders, who are working throughout the whole year to make Europe a better place for young people with IBD. There is always lots of work to do, but we can do it together. If you have some spare time, please try to help in any way you can. We can use every hand that is available in Europe to make EYG and EFCCA stronger organizations for people with IBD.

The EYG is a group of youngsters who work on fantastic projects and activities, especially for children and youngsters with IBD. In this time of easy communication through the internet, and by email, it is easy to reach out to people in need. On our own website (www.efcca.org/eyg), you can learn more about our work and activities. For example, you can find "The Game" - a board game for children and youngsters with IBD. If they're sick, they can easily play this game on their bed, a table, or even on the floor. Just download it, put everything together, and start playing. Our website also has lots of information about how you can help us upgrade the game and translate it into more languages, for all children and youngsters in Europe. There is still a lot of bad practice in schools or workplaces, because many people all around us don't understand what it's like to live with IBD. Teachers might not understand if you need to go to the toilet for the 10th time that day, or a boss might not understand when you take a sick day, if you've had 5 sick days in the last 2 weeks. Maybe even doctors who are graduates in

medicine might not understand all our needs and problems. We need to find solutions to make everyone understand that IBD is an illness that flares-up easily. One day you can feel excellent, but another day you can be running to the toilet every 5 minutes! Doctors need to learn that we are young people who need care on a personal level, as well as a medical level, and we need them to speak to us in language we can understand.

Come and help us - let's make Europe a better place for children and youngsters with IBD.

Chayim Bell (NED – CCUVN)

Marco Greco - EFCCA chairman & former EYG leader

This guide is for every participant involved in the activities of the EFCCA Youth Group. For the “old” ones and for the new ones. It is intended for all the people interested in better understanding us and our job.

During all these years spent working for young people with IBD, it has been possible to see that one of the main issues and problems to cope with is how to avoid wasting experience gained during the meetings.

From this very simple idea, an EFCCA Youth Group project with this principal aim was born in 1999.

The continuous turn-over of participants at meetings (every year we have many new faces, and in these 8 years more than 120 people have attended the event), prompted us to create something to help the “rookies” in getting into the group in an easier and faster way.

We understand it could be difficult to get into the history and the background of this wonderful group, but on the other hand, it is necessary to involve all the participants in our activities. Our strength is in you, dear participant.

You do represent your national association. You do represent a huge number of countries here. And you represent all the youngsters in your country with IBD. If you have been sent here by your mother organization, it is because they are sure that you are an important resource. You have demonstrated strength and iron-will in getting here. Probably for some of you the experience of living with IBD has been very difficult, but you managed to gain the right attitude to work for other people with the same problems, and the motivation of having something important to tell all the other youngsters with IBD. So, this is the moment in which you can express your ideas, your ideals and, why not, your dreams.



Be assertive, be the one on the front line, be the one who has the courage to express a dissenting opinion. Be part of “the creative juventud” that Ernesto Guevara was talking about, because you are that “juventud”.

In other words: start thinking, acting and talking as the leaders of tomorrow .

Marco Greco (ITA – AMICI)

EFCCA chairman, Former EYG Group Leader & EFCCA Youth Group co-founder

Where did it all begin?

In 1998 the German Crohn's and Ulcerative Colitis Association invited active youngsters from a variety of countries for a meeting in the city of Erlangen. The first "international meeting" was born. During the discussion groups, we exchanged ideas and experiences of activities and services for youngsters. Everyone was eager to speak and – perhaps even better – eager to learn! During "free time" we continued our discussions, but then more on a personal level.

We also visited the national IBD meeting for members of the German association in a congress hall. Among other things a variety of interesting lectures were provided (fortunately an Austrian participant was willing to translate the German lectures simultaneously into English for me. Thank you Eva.) During the association's gala dinner that evening we sang as a choir the song "We Are the World", which we rehearsed earlier that day. During rehearsals, not everyone was very enthusiastic about singing ("Do we really have to?!"). Amazingly however when we were on stage that



evening, it was a magnificent experience for everyone (even more amazing, it sounded great as well!)

We wouldn't be youngsters if we did not visit a disco during the late evenings. Some participants had powerful medication for their disease which was for example visible by their 'prednisone heads'. Despite this they joined the group on the dance floor hour after hour.

In Erlangen not only the first international meeting was born, but strong friendships were born as well. Although we spent just a couple of days together, it felt like we had known each other for years. None of us suspected upon arrival that tears would come up

during the goodbyes a few days later.

While we were still in the wonderful mood of the meeting, my fellow Dutch delegates and I promised to organise the next meeting in Amsterdam. A few days later – 'back down to earth' – we realised what a challenge we had created for ourselves. Nevertheless, in 1999 the second international meeting was held.

In Amsterdam we exchanged 'best practice' again, however this time there was an Italian participant who spoke about the idea of developing a European youngsters' commission. And since then he has not let go of this idea. Amsterdam was not ready yet for concrete steps in that direction. However during every following meetings (in London, Stockholm, and Antwerp), the idea became more and more concrete. The next challenge was to convince EFCCA that a youngsters' committee would fit excellently within EFCCA.

It took a lot of time, documents, speeches, meetings and hard work before the actual commission became reality. But finally it did! Definitely an important milestone for young people with IBD throughout Europe. Thanks Marco!

Wouter Miedema (NED)

EFCCA Youth Group co-founder

IBD Research Foundation

Hall of Fame

This page has been added in order to remember and to thank all those people who have devoted their passion, enthusiasm, time and ideas to the creation and development of the idea of the EYG.

Year	EFCCA Youth Group
1999 – 2000	Wouter Miedema (Ned), Marco Greco (Ita), Marlene Backlund (Swe).
2001	Wouter Miedema (Ned), Marco Greco (Ita), Marlene Backlund (Swe), Irene Panhuis (Bel), Heli Haskolin Parjanen (Fin).
2002	Marco Greco (Ita), Irene Panhuis (Bel), Laura Brown (UK), Tom Luyxk (Bel), Nadine Lattimore (Ire).
2003-2005*	Marco Greco (Ita), Irene Panhuis (Bel), Nadine Lattimore (Ire), Susanne Kaplan (Ger), Evelyn Schauer (Aut), + Gillian Hamer-Hodges (EFCCA) & Marleen Reynders (EFCCA).
2005-2006	Marco Greco (Ita), Irene Panhuis (Bel), Susanne Kaplan (Ger), Sanna Lönnfors (Fin), Chayim Bell (Ned), + Gillian Hamer-Hodges (EFCCA) & Marleen Reynders (EFCCA). Subst.: Hajnalka Szabò (Hun) & Carole Lasserre (Fra).
2006-2007	Marco Greco (Ita), Hajnalka Szabò (Hun), Susanne Kaplan (Ger), Sanna Lönnfors (Fin), Chayim Bell (Ned), + Gillian Hamer-Hodges (EFCCA) & Marleen Reynders (EFCCA). Subst.: Ben Wilson (UK) & Heli Parjanen (Fin).
2007	Marco Greco (Ita), Hajnalka Szabò (Hun), Susanne Kaplan (Ger), Ben Wilson (UK), Chayim Bell (Ned), + Gillian Hamer-Hodges (EFCCA) & Arjan Kremer (EFCCA). Subst.: Sanna Lönnfors (Fin) & Heli Parjanen (Fin).
2007-2008	Chayim Bell (Ned), Hajnalka Szabò (Hun), Ben Wilson (UK), Iva Bozicevic (Cro) , Marco Greco (Ita) + Gillian Hamer-Hodges (EFCCA) & Arjan Kremer (EFCCA). Subst.: Andrea Muelhaupt (Swi) & Nicola Baxter (UK).
2008-2009**	Chayim Bell (Ned), Hajnalka Szabo (Hun), Ben Wilson (UK), Iva Bozicevic (Cro), Nicola Baxter (UK) + (EFCCA) & Arjan Kremer (EFCCA). Subst.: Andrea Muelhaupt (Swi) & Daniella Van Hoof (Ned).
2009-2010	Chayim Bell (Ned), Hajnalka Szabo (Hun), Ben Wilson (UK), Iva Bozicevic (Cro), Nicola Baxter (UK). Subst.: Daniella Van Hoof (Ned), Daniel Sundstein (Den) & Ida Persson (Swe).
2010-2011	Chayim Bell (Ned), Ben Wilson (UK), Nicola Baxter (UK), Daniel Sundstein (Den), Maria Salort (Esp) (replaced Ida Persson in Autumn 2010). Subst: Hajnalka Szabo (Hun).
2011-2012	Chayim Bell (Ned), Tiphaine Chapeau (Fra), Arron Gill (UK), Marek Lichota (Pol), Daniel Sundstein (Den). Subst.: Victoria Power (Ire), Stefanie Weber (Ger).
2012-2013	Daniel Sundstein (Den), Tiphaine Chapeau (Fra), Arron Gill (UK), Claire Hunt (UK), Sara Byrne (Ire). Subt.: Victoria Power (Ire), Chayim Bell (Ned), Stefanie Weber (Ger), Margriet Gritter (Ned), Kata Daru (Hun).
2013-2014	Daniel Sundstein (Den), Claire Hunt (UK), Sara Byrne (Ire), Eva Bjornsdottir (Nor), Margriet Gritter (Ned), Subt: Fergal Troy (Ire), Sofie Marton (Swe), Stefan Dakovic (Ser), Maksim Besic (Slo), Kata Daru (Hun), Steffi Weber (Ger),
2014-2015	Daniel Sundstein (Den), Sara Byrne (Ire), Eva Bjornsdottir (Nor), Fergal Troy (Ire), Maksim Besic (Slo) Subt: Claire Hunt (UK), Sofie Marton (Swe), Stefan Djakovic (Ser), Leanne Downie (UK), Katleen Franc (Bel)

(*) = In this year the EFCCA Youth Group joined the EFCCA Youth Group (EYG), officially founded in June 2003, during the meeting in Berlin.

(**) = In this year the observers of the EFCCA attended for the last time.

Previous Meetings

Our meetings from the beginning until now:

- ❖ 1998 – Erlangen (DCCV – Germany)
- ❖ 1999 – Amsterdam (CCUVN – The Netherlands)
- ❖ 2000 – London (NACC – UK)
- ❖ 2001 – Stockholm (RMT – Sweden)
- ❖ 2002 – Antwerp (CCV – Belgium)
- ❖ 2003 – Berlin (DCCV – Germany)
- ❖ 2004 – Rome (AMICI – Italy)
- ❖ 2005 – Edinburgh (NACC – UK)
- ❖ 2006 – Budapest (MCCBE – Hungary)
- ❖ 2007 – Graz (OMCCV – Austria)
- ❖ 2008 – Paris (AFA – France)
- ❖ 2009 – Amsterdam (CCUVN – Netherlands)
- ❖ 2010 – Sommaroy (LMF – Norway)
- ❖ 2011 – Cracow (J-elita – Poland)
- ❖ 2012 – Copenhagen (CCF – Denmark)
- ❖ 2013 – Stuttgart (DCCV.e.V. – Germany)
- ❖ 2014 – Dublin (ISCC – Ireland)
- ❖ 2015 – Tampere (CCAFIN – Finland)

Awards

Starting in 2004 in Rome, a special award is presented each year. The award is intended as recognition of great work, but also as a good reason to have fun during the annual “Loekie awards night”.

The most important prize is the “Loekie award”, and it goes to the national association that during the year has managed to realize a project that fits with the criteria indicated by the EFCCA Youth Group and the EYG. This prize is not given to a single person. Usually it consists of a “plate” and a special diploma. In 2004 the plate was designed by Maria Grazia Bendazzi (ITA), while in 2005 it was designed by Silvia Poldi (ITA), who also designed the plate for 2006 as well.

Smaller awards are assigned too. These are typical prizes for all kinds of achievements. Something funny or witty, for participants who have fulfilled some specific tasks (like becoming adults!).

Here is the list of the awards presented in each year:

<p>Rome 2004:</p> <p>Loekie Award (best project) – CCV – Belgium – “Holidays abroad for youngsters with IBD”</p> <p>Loekie Award “Career” – Wouter Miedema (NED)</p> <p>Special Loekie Award (“Highest participation at a meeting”):</p> <ul style="list-style-type: none"> • Cecilia Liimatainen (SWE) • Marco Greco (ITA) 	<p>Edinburgh 2005:</p> <p>Loekie Award (best project) – OMCCV – Austria</p>
<p>Budapest 2006:</p> <p>Loekie Award (best project) – NACC – United Kingdom – “IBD and Me – a web forum for young people”</p> <p>Sporting activity (football): Ben Wilson (UK), Nicola Baxter (UK), Nadine Lattimore (IRE), Gabi Kameritsch (AUT), Susanne Kaplan (GER), Concetta Balzotti (ITA), Hajnalka Szabò (HUN), Maria Salort (ESP), Heli Parjanen (FIN), George Fysentzou (CYP), Marco Greco (ITA – Captain).</p>	<p>Graz 2007:</p> <p>Loekie Award (best project) – AFA – France – “A film – a portrait of uncommon young people with IBD”</p> <p>Orange ribbon – Rod & Myra Mitchell (UK), Wouter Miedema (NED) and Evelyn Schauer (AUS)</p>
<p>Paris 2008:</p> <p>Loekie Award (best poster) – DCCV – Germany</p> <p>Orange ribbon – Susanne Kaplan (GER), Gillian Hamer Hodges (UK) and Irene Panhuis (ITA)</p> <p>Sporting activity (treasure hunt around Paris) – winning team – white bandana team.</p>	<p>Amsterdam 2009:</p> <p>Loekie Award (best poster) – CCF – Denmark</p> <p>Orange ribbon – Marco Greco EFCCA Chairman (ITA), Mr and Mrs Bell (NED) and Luisa Avedano, EFCCA CEO (ITA)</p> <p>Sporting activity (game of rounders) – a draw between the two teams</p>
<p>Norway 2010:</p> <p>Loekie Award (best poster) – ACCU - Spain</p> <p>Orange Ribbon – Arne Schatten (NOR), Sanna Lonnfors (GER/FIN), Marlene Backlund (ZWE)</p> <p>Sporting activity (fishing) – Ingrid’s team</p>	<p>Poland 2011:</p> <p>Loekie Award (best poster) – J-Elita – Poland</p> <p>Orange Ribbon - Jeanette Richardsen (NOR), Ingrid Milde (NOR), Hajnalka Szabo (HUN/ITA)</p> <p>Sporting activity (City games) – a draw between the four teams</p>

Denmark 2012:	Stuttgart 2013:
<p>Loekie Award (best poster) – SMCCV – Switzerland</p> <p>Orange Ribbon – Ben Wilson (UK)</p> <p>Sporting activity (Beach volleyball) – Team B</p>	<p>Loekie Award (best poster) – KVCB – Slovenia</p> <p>Sporting activity (Alternative decathlon) – Team Daniel</p>
Dublin 2014:	Tampere 2015
<p>Loekie Award (best poster) – CYCCA – Cyprus</p> <p>Orange Ribbon – Chayim Bell (NED)</p> <p>Sporting activity (Treasure hunt) – Benny Epand (Israel), Bianca Heusler (Switz), Katleen Franc (Bel) and Nasia Charalampous (Cyp)</p>	<p>Wait & see!</p>