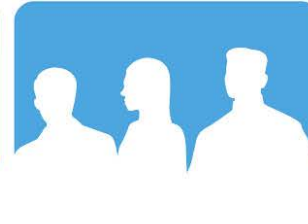
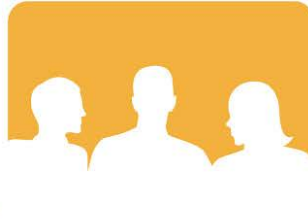


ANNUAL FAMILY MEETING

Yunus Borowczak
Parents' Organisation for Children with CML
Germany

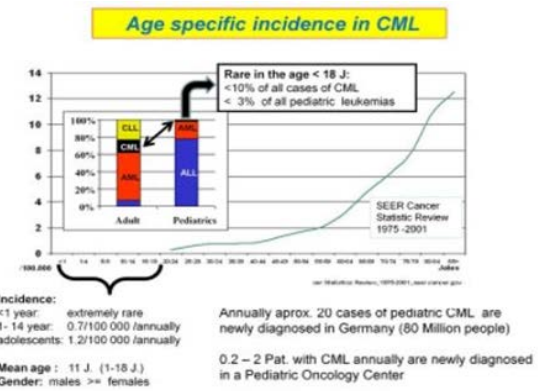
Advocacy Session #4
Best practice in patient advocacy
#CMLHZ17





Background

- CML is a rare disease in childhood and adolescents
 - 10% of all cases of CML
 - 3% of all paediatric leukemias
 - approx. 20 new cases in Germany annually
- (Courtesy of Prof. Dr. M. Suttrop)



2006: due to the lack of available information for parents www.cml-bei-kindern.de was created

2007: the first family meeting was organised to bring families with common concerns together

2011: „Parents‘ Organisation for Children with CML e.V.“ was founded to organise and finance annually meetings and events more easily

Implication

Children and adults emerge stronger due to face to face meetings

- First family meeting in 2007 with 28 participants from 7 families
- Follow meetings in 2010-2015 & 2017 with growing groups
- Past meeting in February 2017 with 79 participants from 21 families
- Therefrom 19 children and adolescents with CML in the age of 7 - 25



Annually family meetings

how to plan and implement

- **Duration**
 - *only one day meeting or for a whole weekend*
- **Identify a number of participants**
 - *family size, age structure*
- **Location**
 - *central, easy to access, catering, accomodation*
- **Financing**
 - *privat donations, pharma, foundations*
- **Objectives**
 - *exchange of experiences, new learnings, get to know each other*
- **Program and Lectures**
 - *speakers, events, games*



3 Days Family meeting 2017

Day 1:

arrival, welcome dinner, get together with introduction of participants, warm welcome for 3 new families, separate welcome for children offered by childcare workers, nightwalk for adventurous families

Day 2:

full-day session for parents and interested adolescents offering by Prof. Dr. Meinolf Suttorp, the German CML expert for children, leisure activities in age groups for children (paint & craft, play games, ATV tour), joint dinner

Day 3:

family adventure game, exchange of information and experiences among the families, farewell



Results and Impact

- Time to exchange information and personal experiences
- Gaining a greater knowledge & understanding
- Learn how to deal with side effects and adverse reactions
- New friendships and experiences
- Become aware that there are families with same worries and concerns
- Emerge of strength due to cohesion and mutual support

„I have learned that I can do everything despite of CML“



„For us as parents it's good to share time with other effected families“

„Beverages were free and I mustn't take care of the costs“



„I have seen how other deal with side effects and everything is feasible“

„I have never played such a big game with my parents „



„Childcare workers were so nice“



Conclusion and recommendation

- Meetings with 2 overnight stays offer the possibility to organise a balanced mix with medical sessions, joint activities and personal exchange
- Search for financial support by foundations or pharma companies
- Build an organisation team to avoid all organisational work will burden on one shoulder



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