



Berlin, den 21.12.18

Dear parents, members, supporters and network partners,

We would like to take the forthcoming Christmas and the turn of the year as an opportunity for a brief look back and look forward and have compiled the following information concerning our association and our common topic "Living with hyperinsulinism".

About our association 2018

- ✓ This year the regional groups met in Düsseldorf, Heidelberg, Vienna and Hamburg for the Day of Rare Diseases. We want to be local contacts as well as strengthen regional groups. Our mentoring program is to be established here. The focus is on personal exchange between families and we are supported by physicians.
- ✓ During this year our sponsors cared for new families. In the hospital or on the phone, we give from heart to heart and make wonderful friendships across borders. Going the way together gives us strength and power.
- ✓ This year 14 new families joined the association. We grow and become stronger together. We welcome new families from Bosnia, Croatia, Switzerland. We are strongly represented in Europe and through our international cooperation we are well positioned to help anyone who has a affected family member with CHI.
- ✓ This year we were repeatedly asked for help by families from non-European countries and were able to support them. Our help with the applications for "Ein Herz für Kinder" was able to raise funds and enable the families to receive treatment in Germany.
- ✓ At the beginning of the year 2 members were at the transition workshop of the Umbrella Association Kindernetzwerk e.V. to be trained as transition coaches. We would like to deepen the topic in the association for our young people and their way into self-employment and integrate it into our plan 2019.
- ✓ We were part of the CHI International Family Conference in Athens and at the ESPE Athens we informed more than 250 international congress participants about our work at the CHI international information booth.
- ✓ We applied for our 4th project grant for our project "PEAK - Participation and Empowerment of Children with Congenital Hyperinsulinism and their Parents". BARMER exclusively supported our project with 14.353,75 Euro. We would like to thank them for their support.

- ✓ Our annual Parents' Meeting took place for the 9th time in Berlin and for the "Annual Meeting", because our teenagers and young adults have their own conference content and can help shape their own program. With the financial support of BARMER, the weekend could once again be organized free of charge for all club members. This year, Julie Raskin from CHI international was our guest of honour. We intensify our cooperation for common goals. Julie presented her work. In the evening we admired Berlin at the "Festival of Lights". On Sunday our annual meeting was rounded off by a joint visit to the Berlin Zoo.
- ✓ In close collaboration with the CHI-International Group, represented by Julie Raskin, our association helped to launch the "Global Registry". Our goal to offer the registration in German is in progress.
- ✓ On November 17, 2018, CHI International hosted the "Donations Collection Auction" the Sugar Soirée in New York. We have contributed with participation and financial support to help CHI children, worldwide, get access to therapies and treatment.

Outlook 2019

- Regional meeting in Düsseldorf on 23.02.2019
- Regional meeting in Heidelberg on 16.03.2019
- Regional meeting in Chur (Switzerland) 13.04.2019
- Regional meeting in Hamburg on 09.03. or 18.5. 2018
- Annual meeting in Berlin-Weißensee on 21-23.06.2019
- "PEAK goes international" in Vienna on 20-22.09.2019



The largest project in 2019 has been planned for years and is to be implemented in Vienna. Our association and CHI-international together organize the Family Conference. The Vienna Regional Meeting this year take place on 21 September. We would like to invite you to our biggest event for CHI families ever! Come to Vienna in September 2019 and be part of a big community! Unfortunately, we need every financial support, because a project promotion of the German health insurance companies is not possible in Austria. We have members in Austria, Switzerland, Slovakia, Croatia, Bosnia, Serbia, Sweden, the Netherlands and Germany. International CHI specialists will be there for us. **Help to collect donations for "PEAK goes international in Vienna 2019"!!**

Christmas greetings

We look back on an exciting, exciting year and thank you for the many interesting encounters and the valuable support that our association has experienced. At the same time, we were also able to provide a great deal of help and support for newly affected families. We are looking forward to the continuation and deepening of existing cooperation's and the establishment of new contacts. We wish you a Merry and peaceful Christmas and a Happy New Year 2019!



Your executive Committee