***Circa May 2016:***

Comics4Kids have again graciously provided new comic books to be donated to the Children's hospital play room and/or patients. Of course, this is in continuation of honoring our dear angel Yasmeen and continuing to share her light by giving back to Children's.

While it was so fun to have HitchBat join us last time and share the light, this time will just be a drop off. Kadri, Yasmeen's mom of course, thought summer is the perfect time when the kids may not be able to get out and this would be something to occupy some time.

We had some very exciting news! Due to some foot work that I did along with the Congenital Disorder of Glycosylation (CDG) group of parents and researchers, our WA state governor Jay Inslee issued a ceremonial proclamation making May 16th WA state CDG day!! May 16th is the birthday of Professor Jaak Jaeken, MD, PhD the medical doctor that reported the first CDG patients more than 30 years ago. We are shooting for May 16th to be world CDG awareness day!

Thank you all for your initiation and effort!!!

Hilja



**About CDG CARE**

CDG CARE (Community Alliance and Resource Exchange) is a nonprofit organization founded by parents seeking information and support for a group of disorders known as Congenital Disorders of Glycosylation (CDG).

Our mission is to promote greater awareness and understanding of CDG, to provide information and support to families affected by CDG, and to advocate for scientific research to advance the diagnosis and treatment of CDG.

We will uphold our mission by:

* Providing information and support to individuals diagnosed with CDG, their families, and the professionals who work with them
* Increasing public awareness and understanding of CDG
* Developing a resource of programs and services to help individuals build strengths and meet challenges from early childhood through adulthood
* Encouraging and supporting research into a wide range of issues related to CDG

Our Vision… *Where CARE Grows…*

* *CARE Grows*… with every new patient who is properly diagnosed
* *CARE Grows*… as donor commitment broadens to support new educational and research opportunities
* *CARE Grows*… with every medical and therapeutic advancement that leads to improved care
* *CARE Grows*… as global collaboration and partnerships raise awareness and strengthens the future for our Community

**Share Your Story** – We are collecting family stories and photos to serve as a resource to newly diagnosed CDG patients and as a reference for all medical professionals.  Please email us at [info@cdgcare.com](mailto:info@cdgcare.com) to contribute to this important initiative.

**Join the CDG CARE Board** – We are continually looking for additional individuals willing to serve on our Medical Advisory Board. Our Boards consist of a diverse representation of qualified individuals who have the time, passion, talents, and resources to help CDG CARE fulfill its mission and achieve its strategic purpose.  If you are interested in helping us to promote and advance our efforts throughout North America, please email us at [info@cdgcare.com](mailto:info@cdgcare.com).

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**Disclaimer**  
  
<http://cdgcare.com/about-us/>

The CDG CARE website is a forum for the free expression of ideas created by, and for, parents of children diagnosed with Congenital Disorders of Glycosylation.  The information provided on this website should not be used as a substitute for seeking a professional medical diagnosis, treatment or care.  You should not rely on any information provided through this website as a replacement for medical consultations with qualified health professionals.

**Privacy Policy**

CDG CARE is committed to protecting the privacy of visitors to our website.  We respect and protect the privacy of all who visit, use and submit information to the CDG CARE website. Individually available information about you is not disclosed to any third party without first receiving your permission.

**HitchBAT and Friends at Seattle Children's Hospital**

Thanks to [Charlotte](https://www.facebook.com/CharMer82) (AKA Charley) and [Chris Kim](https://www.facebook.com/chriskim1971), [HitchBAT](https://www.facebook.com/hitchBAT/) made it up to Seattle and brought smiles to our family!! Charley drove HitchBAT up from LA with her wonderful 15 year old cat Grim Malcolm. HitchBAT made some friends along the way!! Kadri, Ahmad's, HitchBAT's and Soos' 40 minute flight was through [Seaplane Scenics](https://www.facebook.com/seaplanescenics/). James, Alicia and their pilot Tom knew that this flight was about our recent loss of Yasmeen and they fully supported getting HitchBAT on the plane to bring more smiles!!! Kadri took some amazing photos from the air and of HitchBAT in the air. This visit is about our dear Yasmeen! Her light continues to shine on us and she's always with us!! [#hitchbat](https://www.facebook.com/hashtag/hitchbat)

November 23 · · [Seattle Children's Hospital](https://www.facebook.com/seattlechildrens/)

What a blessed day at Seattle Children's Hospital with my daughter Kadri, grandson Soos, Luckie Seibert and her husband Mike, HitchBAT and the comic book donations from Comics4Kids, [Chris Kim](https://www.facebook.com/chriskim1971) and others. It was a success! Thank you all for being part of it!!! Yasmeen’s light shines through!   
While it was mainly younger kids in the playroom, Seattle Children's Hospital staff Sheira and Lina both said that teens are a population at the hospital that will love getting the comics up at their rooms. For privacy, we did not take photos of all the kids receiving comics and meeting HitchBAT. The two in the photos had parent permission to share their photo.   
Comics4Kids said they would love to do this on a yearly basis right around Thanksgiving in Yasmeen's honor. She was born on Thanksgiving day! Luckie, Chris, Kadri and family said they will participate too if possible!! We are forever grateful for these new friends. On this journey with HitchBAT, I said that the Universe was conspiring with us for the highest healing good and that has been very true!! There were multiple coincidences that make us believe a higher spirit was guiding the whole process. We could not have planned it better! Thank you all including [Charlotte](https://www.facebook.com/CharMer82) who brought HitchBAT all the way up here for us and [Jeanette](https://www.facebook.com/jeanette.l.miller.7) who introduced me to him!!! Remember to send up the HitchBAT signal if you too need HitchBAT and his good in your life! [#hitchbat](https://www.facebook.com/hashtag/hitchbat)