

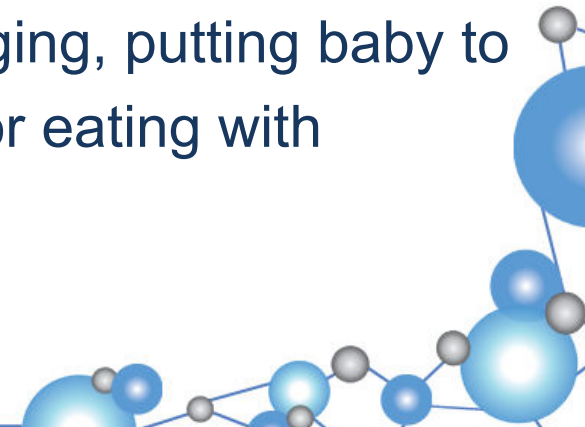
The Psychosocial Burden of Congenital Hyperinsulinism

A Global Insult to the Family

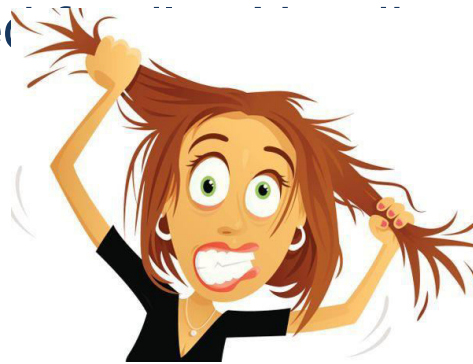
- Counterintuitive for a baby to be sick
- A strange disease we don't understand
- Extended stay in a hospital
- Feeling powerless. We can't make our baby well.
- Once home, its as if we are still in the hospital. We have one goal, keeping blood sugars in a safe range



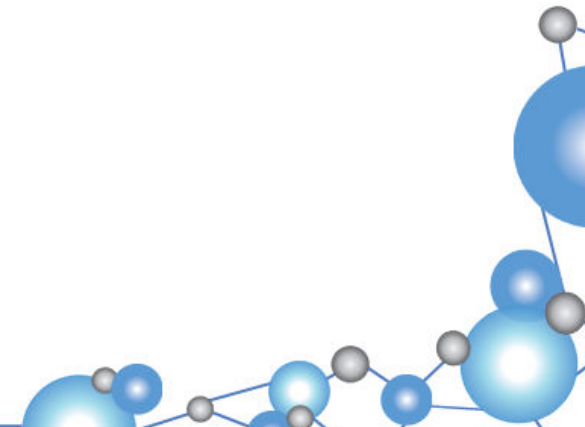
- Baby or child doesn't want to feed.
- Life revolves around these feedings.
- Need to get the food in to prevent brain damage.
- But don't want to cause an eating disorder.
- Strange HI Family Meals (TV, coaxing, begging, putting baby to sleep to trick them eating, never going out or eating with friends).



- Goal is blood sugars in control. Result is family out of control.
- Stress with partner. Whose in charge? No time for relationships.
- Stress with other children. Not enough time to give to them.
- Stress with extended family. Not wanting to relinquish control.



help, not wanting to

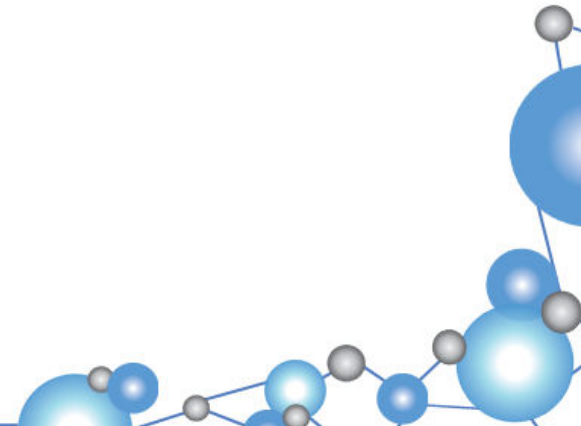


- “Their” kids are not sick and are developing normally. Jealousy. Fear of benchmarking our HI kids to their normal kids.
- Feeling excluded from “normal gatherings.” Not wanting to be labeled the “depressed one.”
- Not having time to spend with good
- No time to make new friends.

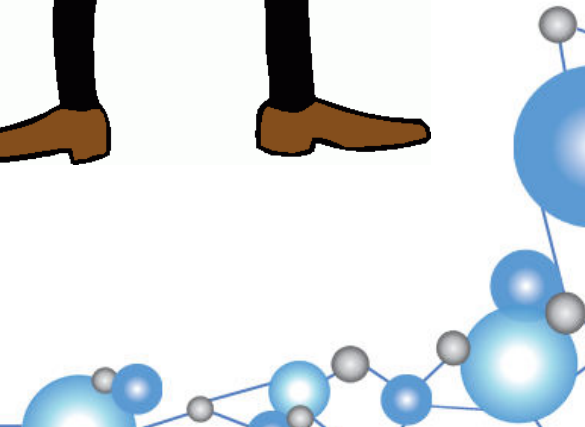




- Living for the numbers
- Hyper-focusing on the difficulties
- Nothing else is interesting

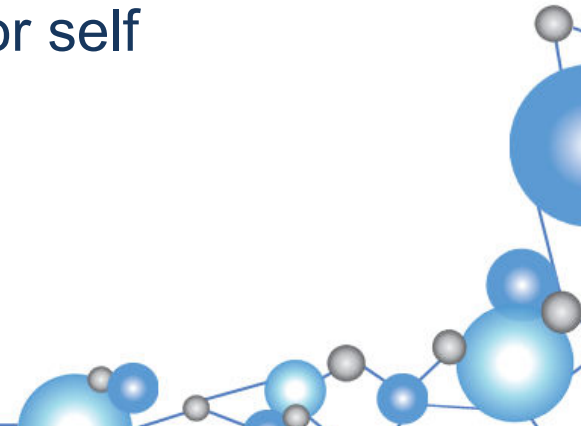


- Treatment is expensive
- Traveling to centers is expensive
- No time to work. Have to care for my kid.





- Not sleeping enough
- No time for self
- No time for fun
- No time for healthcare appointments for self



- Seeking professional help when we need it.
 - Joining support groups and seeking help from advocacy organizations.
 - Training family members and friends. Letting them help. – coupled with making time for self and relationships, reading and hobbies
 - Allowing ourselves to be good enough parents.
 - Creating a pathway back to work or a new kind of work, if necessary.
 - Welcome to Holland metaphor – imagining a different present and a different future.
 - Allowing ourselves to feel joy again.
 - The Harvest.
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