Your Child was Just Diagnosed with Diabetes...

Now What?

PEP Squad
Parents Empowering Parents

Diabetes Research Institute Foundation

National Office
200 South Park Road, Suite 100
Hollywood, FL 33021
954/964-4040 800/321-3437 Fax: 954/964-7036 info@drif.org

Northeast Region
381 Park Avenue South, Suite 1118
New York, NY 10016
212/888-2217 Fax: 212/888-2219 neregion@drif.org

Long Island Region
410 Jericho Turnpike, Suite 201
Jericho, NY 11753
516/822-1700 Fax: 516/822-3570 liregion@drif.org

proud partner
Walgreens

sponsored by
Carnival Corporation & PLC
Dear Parents,

You have just been given the life-altering news that your child has been diagnosed with type 1 (juvenile) diabetes. You will experience a wide range of emotions during this time and this guide will help you deal with them, as well as give you information on how to go on living your life with your child’s diabetes. It is written by parents who are part of the PEP Squad (Parents Empowering Parents). We have all shared similar experiences and are here to give you moral support and help put you back on track to being a happy, well-adjusted family. Take heart and remember the PEP Squad is only a phone call away to help you through this difficult time, answer your questions and alleviate your fears.*

Most sincerely,
Moms and Dads of the PEP Squad

"While our children live with the daily challenges of diabetes, we all deal with it as a family and remember that our kids are kids first."

To be connected with a PEP Squad member in your area, call the Diabetes Research Institute Foundation at 1-800-321-3437. To learn the latest information on research toward a cure for diabetes, visit DiabetesResearch.org.

Search “PEP Squad Group” on Facebook.
Diagnosis: What does this mean?

As the doctor delivers the news, your initial reaction is usually shock, then denial. “How can this be happening?” “We have no family history.” “The lab reports must be incorrect.” These may be some of the phrases running through your mind. The difficult but simple truth is that type 1 diabetes is a chronic condition where the body’s pancreas no longer produces insulin; therefore your child will require insulin to survive. No one understands exactly why this happens, and presently there is no cure. As unfair as it seems, a child's diagnosis is something we all just have to, in our own time and in our own unique style, learn to accept. The sooner you understand and acknowledge this fact (with the help of friends and professionals), the easier you will move on. There is no family member or life event that causes diabetes and therefore, no one to “rationally” blame. The legitimate need to blame comes from grief, from needing a place to put the anger from being diagnosed.

While in the hospital, you will receive a crash course in diabetes management. You will probably learn about blood glucose testing, insulin dosages and
injections, meal planning, carbohydrate counting, exercise, sick day management and emergency medical procedures. You are very concerned with your child’s health, but if you allow the doctor and hospital staff to attend to your child, you can concentrate on what you need to know to care for your child at home. It is important to pay attention, take notes and learn all that you can during this critical time. In the midst of this life-changing event, with all of its accompanying anxieties, you may forget some of this information. Realize that most parents have little or no knowledge about how to care for a child with diabetes prior to diagnosis. Try to drop the anxiety about perfection and just do the best job you can and continue creating opportunities to learn from medical professionals and other families. You and your spouse will also respond and learn differently, with one parent usually taking the lead and assuming the majority of the responsibility. This does not mean your partner cares any less; in fact, the different styles serve to balance each other and the family. Periodically the primary caregiver will need a break, which will require effort and willingness on both parents’ part.

The New "Normal"

When you return home, you will probably feel overwhelmed and wonder if life will ever be the same. Truthfully, it’s not. However, you will come to know a “new normal,” which includes happiness along with routine aggravation. Once your child is stabilized and you are comfortable with the day-to-day diabetes care, you should encourage him/her to resume all regular activities. This will take effort, trust and resiliency on the parents’ part to educate relatives, teachers, coaches, babysitters and others who will be caring for your child. Be armed for their resistance and your reluctance of them not doing it as well as you. They’re right; they won't. However, it will be “good enough,” and it sends an important message to your child that there are other people besides parents who can take care of his/her needs.

At a minimum, training should include blood glucose testing and instructions on when to give juice, food, or glucagon. It is also important to teach others how to recognize signs of low blood sugar, which could include: shaking, sweating, confusion, dizziness, slurred speech, poor coordination, irritability, etc. These symptoms will vary with each child, and with time, you will learn how your child reacts. Depending on their age, some children are willing to take on some of their own diabetes care and should be given the opportunity. The ability to have some control over their condition can help kids cope.

You’re Still a Family

Parents often feel anger and grief about a diabetes diagnosis. It is normal to ask, “Why me?” and to be angry over the changes imposed on your life. Watch out for short-term versus long-term martyrdom,
anger or fear. Family relationships and marriage can be affected and so can your relationship with your child with diabetes and your other children. Diabetes is best managed when the entire family is involved. This can actually be a positive situation when the whole family adopts better eating and exercise routines, and it will make the child with diabetes feel not so isolated or different. There will be resentment and sadness at times, and it is important that everyone communicates all feelings and needs to each other. Remember, there are or may be other siblings who are angry at the new limitations placed on their lives and the amount of attention focused on diabetes. You should not feel sorry for your child with diabetes, nor feel as though you are punishing or depriving other family members. As with all families, it is important to try to balance everyone’s social, emotional and physical needs. At some time, your family might need professional support from a social worker or a psychologist. There is no reason why your family cannot participate in the activities you love. It just requires some advance planning in terms of the timing of meals and having insulin and other medical supplies with you. With the variety of high-tech medical devices available, along with personal experience, you will find out what works best for your family. With time, you will all gain strength from your child with diabetes when you discover the resiliency and empathy your children develop.

Your Child is a Child First

Remember, your child with diabetes is always a child first, more than an accumulation of blood sugar readings. Try not to comment about a reading being good or bad (it’s just a number), because at times children may feel or actually be responsible for having caused their less-than-perfect reading. This should not be linked to their self-esteem or yours. We are human, not perfect. Try to be matter of fact. Fix the problem and move on. It can also be useful to ask your child what may have caused the high/low blood sugar and let him/her help with the problem solving, without judgment. Just by talking with your child, you will be able to determine whether he/she is ready, willing and able to take on some or all of the management of diabetes. Not only will it give parents a much-needed break, it will build your child’s confidence and self-esteem. Your trust will empower your child to make decisions on his/her own. This is a valuable lesson for any young person to learn, and you will find your child with diabetes may be ahead of peers in this regard.

Heal the Hurt

Accept that diabetes is difficult to manage. Control will probably never be perfect, however with diligence it can improve. Balance will be a challenge to maintain, especially when food, insulin, exercise, illness and stress are all factors affecting blood sugar. In fact, our own bodies don’t regulate blood sugar...
“perfectly” either. Don’t internalize or let your mood be altered by fluctuations in blood sugar readings. Keep in mind that the general health and well-being of your child are most important, and remember once again, your child with diabetes is always a child first.

The idea of living with diabetes for many years and the risk of complications can be overwhelming, so it is important to keep a positive outlook and take care of it one day at a time, while allowing for periods of burnout. An optimistic attitude can go a long way toward influencing your child’s behavior and acceptance of his/her diabetes. Search for inspiration and motivation by meeting other families who have children with diabetes, attending conferences or retreats, participating in fund-raising activities, keeping up-to-date on medical research and technology, and reaching out to family, friends, medical professionals or a support group when necessary. Most importantly, continue to live your life fully while helping your child to maintain the best of health and happiness with the hope that one day there will be a cure.

Written by:
Lynette Miller, B.A., M.B.A.
Mother of Lauren, Jake, Zach and Brooke, who has type 1 diabetes

In consultation with:
Wendy Satin Rapaport, Psy.D., L.C.S.W. Clinical Psychologist
Robin Nemery, M.D. Pediatric Endocrinologist

The Diabetes Research Institute, a center of excellence at the University of Miami Miller School of Medicine, is a recognized world leader in cure-focused research. Since its inception in the early 1970s, the DRI has made significant contributions to the field of diabetes research, pioneering many of the techniques used in islet transplantation. From innovations in islet isolation and transplant procedures to advances in cell biology and immunology, the DRI is now harnessing the power of emerging technologies to develop new cell-based therapies to restore insulin production. For the millions of families already affected by diabetes who are looking to the world of science for answers, the Diabetes Research Institute is the best hope for a cure.

* Terms of Use: Any and all information included in this brochure is for general information and/or educational purposes only, and should not be construed as medical advice, medical opinion, diagnosis, treatment or professional services of any kind whatsoever. Any information provided by the Diabetes Research Institute Foundation/Diabetes Research Institute and/or this brochure is not a substitute for medical attention. See your licensed healthcare professional for your medical advice and treatment.
Get connected with a member of the PEP Squad. Please complete the form below, and you will be contacted shortly.

<table>
<thead>
<tr>
<th>Child's Name</th>
<th>Date of Birth</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td>Date of Diagnosis</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td>Mother's Name</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td>Father's Name</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td>Address</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td>City</td>
<td>State</td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td>Daytime Phone</td>
<td>Evening Phone</td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td>Email</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
</tbody>
</table>

"...Continue to live your life fully while helping your child maintain the best of health and happiness with the hope that one day there will be a cure."

Cut at line and mail form to:

PEP Squad
Diabetes Research Institute Foundation
200 South Park Road, Suite 100 Hollywood, FL 33021
pepsquad@drif.org