


MY GRANDCHILD HAS PRADER-WILLI SYNDROME. NOW WHAT?

e-booklet written by Barbara McManus and Michele Leightman

The discovery that your grandchild has Prader-Willi syndrome (PWS) can be quite a shock. This booklet is meant to be used as a resource to help provide encouragement and strength to face the unknown. It will offer an opportunity to understand how you as a grandparent can get help for yourself and offer help and support for your family. The contents of this booklet were gathered from responses to questionnaires that were distributed to parents and grandparents of children with PWS.



Gary and Alita Brisendine
with London Harless


Prader-Willi
SYNDROME ASSOCIATION (USA)
SAVING AND TRANSFORMING LIVES

GRANDPARENTS OF CHILDREN WITH PRADER-WILLI SYNDROME

I came to be the grandmother of a child with Prader-Willi syndrome through marriage, and little did I know at the time what a special grandson Reagan was going to be. When I look at him, I do not see a child with PWS, but rather I see Reagan, a very special young man. I am ashamed to say I had never heard of PWS, though I had been a registered nurse for over 35 years. I officially joined the Seely family when I married Reagan's Grandfather, Bob, in 2010. Shortly after our marriage, Reagan's parents, Rob and Diane, told me they had been discussing suitable names for Reagan to call me, and asked me what I thought of 'Nana.' My heart skipped a beat, as it was a wonderful term of endearment. I had never been called 'Nana' by anyone. Maybe Grandma or Granny, even Mermaw. But Nana belonged to Reagan and me, and it did not take long for us to settle into it. I finally felt a part of the Seely family, and to this day, when Reagan says 'Nana,' it just melts my heart. He is not a 'step-grandchild,' but my Grandson, and I am so very proud of him, as all grandparents are of their grandchildren.

Prader-Willi Syndrome is often referred to as a broad-spectrum syndrome, exhibiting many different symptoms and challenges. It does not discriminate between sexual identity nor race. Boys and girls around the world are diagnosed with PWS every day, although third world countries often present special challenges in the diagnosis and treatment of PWS. I understand that clearly now, but the story I am going to share is not one of fact or science or medicine, but of the heart.



Grandma and Reagan Seely

I spent 20 years of my life caring for AIDS orphans in Zimbabwe. In fact, that is where I met Reagan's Grandfather. In 2003, Bob visited the children's home I was running, and he returned in 2004 to assist with our building program. In 2010, after a long friendship, we married; he fell in love with my orphans. I fell in love with Reagan. But the story does not begin there. Years prior to that, shortly after I arrived in Africa, full of hopes and dreams, I was instructed to work for 6 months in a government hospital to familiarize myself with the maShona culture, tropical diseases, and terminology, including the maShona language.

During that time, I was assigned to work on the Pediatric Oncology Unit at Parirenyatwa Hospital (Dr. Parirenyatwa was the first African National to earn his medical degree from the all-white University of Rhodesia). Emotions were constantly challenged with heart-wrenching cases of cancer in little ones. One afternoon, after I had simply given a few minutes of listening time to a broken-hearted mother, she said to me in the MaShona language, "Ndinotenda Mbuya" (Interpreted literally, "I thank you Grandmother.")

I stood behind the desk, somewhat stunned at having just been called a grandmother, for I was just shy of my 35th birthday and I had an infant myself at home. I thought to myself, "She is either blind or crazy, because I know I do not look like a grandmother." I continued with my work, but I could not shake the feeling that I needed to ask someone why she had called me 'Grandmother.'

As I was musing to myself, a respected co-worker came to the desk and I told her the story. She gained a large smile on her face and said, "Nisi, you are now truly 'one of us.' You see, to be called a Grandmother is the highest honor any African could give you, because it simply means you have lived life, you understand many things, and your time has come to be respected. It has nothing to do with your age. She is simply saying 'I respect you.' In our culture, it is the highest gift you can give someone. You should feel honored!"

"Oh, I do," I tried to convince her, yet somewhat still stunned. "However, in our culture to call a 35-year-old woman a grandmother could be an insult. It just took me by surprise, that is all."

And so that day I learned a little more maShona culture, and it was something I was to hear many more times before leaving my beloved Africa. To this very day, I always consider it an honor when someone calls me a grandmother, telling them my ten grandchildren (and one to come!) are jewels in my crown. (Proverbs 17:6). Except now there is a very special young teenager in Ohio who has substituted the word to Nana, though it means the same thing.

So, call it what you may: Grandmother, Grandma, Granny, Mermaw, or Nana. It is a title of respect that is never to be taken for granted. It does not mean that we have to be anybody special, it just means that we have to be willing to love and share ourselves with those who love us just the way we are, just because we are their 'Nana.'

And so, this is dedicated to you, Reagan, for allowing me to be your Nana. It is a gift I will never take lightly, and my prayer is that I will leave a small part of my being with you to remember, to hold on to and to respect. I learned that lesson in another time and another place, yet I will continue to do all within my power to help you become everything you are capable of being. Grandparents are an important and integral part of any child's life, and I want you to know that I am so proud of you, Reagan, and you continue to amaze me. I wonder what word there is to convey that to Reagan? Yes, I know! Grandson! "Ndinotenda Mukorore!" ("I thank YOU my Grandson!")

Written by Reagan's Nana, Nisi Seely

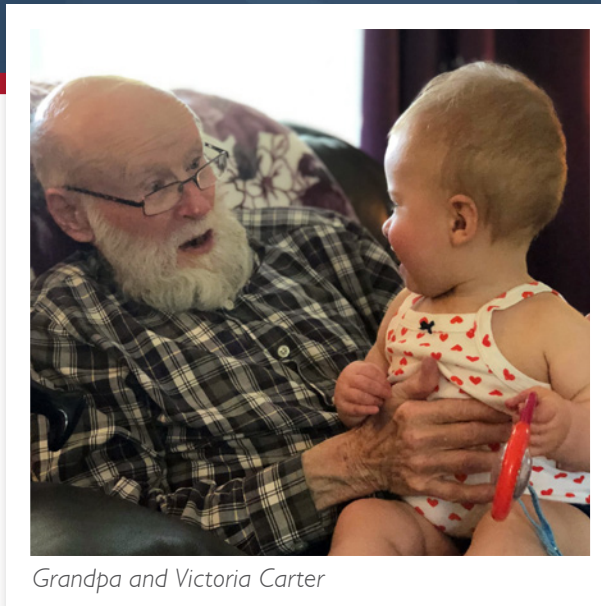
YOUR GRANDCHILD HAS PRADER-WILLI SYNDROME

The discovery that your grandchild has Prader-Willi syndrome (PWS) can be quite a shock. This booklet is meant to be used as a resource to help provide encouragement and strength to face the unknown. It will offer an opportunity to understand how you as a grandparent can get help for yourself and offer help and support for your family. This booklet is not meant to give detailed information about Prader-Willi syndrome itself; please refer to PWSA (USA) for materials for that purpose. The contents of this booklet were gathered from responses to questionnaires that were distributed to parents and grandparents of children with PWS.

Many grandparents learn their grandchild has PWS through the parent, their own child. This is a difficult and emotional period of adjustment for all. You may feel disappointed that your dreams of baking holiday cookies with your grandchild, and having big holiday feasts will not be as you thought. Though the picture may look different than what you had imagined, it is important to remember that in time, you will again feel the joy of sharing family holidays and celebrating happy occasions with your children and grandchildren.

WHAT CAN I DO TO HELP?

Many grandparents today are still in the workforce, and many others are enjoying retirement. Most of our children recognize that we can be a real asset in their lives, and most of us want to help in any way we can. Find out what you can about Prader-Willi syndrome. Reach out to the many medical providers, professionals and volunteers that can answer your questions and address your family's concerns.



Grandpa and Victoria Carter

Understand that you are not alone, and allow yourself to gain strength and support from others. Recognize that each person deals with the shock and grief of the diagnosis in their own way, and be tolerant of these differences. Remain hopeful, and encourage all involved to get through the ups and downs together.

Listen, Be There

Perhaps the greatest service you can offer is to listen when your children need to talk. Most grandparents have found that listening and not passing judgment or giving unsolicited advice is a gift deeply appreciated by their sons and daughters. Your child (the parent) needs you now. His or her family needs you, too. The unexpected challenges created by the syndrome are an adjustment for everyone. There is no one to blame for this rare disorder- it just happened. Denial, anger, sadness, and isolation are some of the emotions normally experienced by everyone; time will be needed to work through them. Be aware that different feelings will come and go, and that it is common for each person to experience these emotions at varying times and levels of intensity. Create a safe environment for the exchange of conversation, but most of all, be there to listen.



Grandma and Isla Selinger

Share Your Own Feelings

Share your own feelings with your child (the parent) when, and if, they are ready. For some of us, sharing our thoughts and fears with our children may be beneficial and may make it easier for our children to open up to us. For others, sharing these things may have the opposite effect. Although they care about you, some parents may be on overload, and be unable to handle more than the basics of day-to-day survival. For grandparents, the diagnosis is a "double whammy" because they hurt for their new grandchild, as well as for their child. Try to be sensitive to your children's needs without sacrificing your own. Help and support are available through PWSA (USA). Just call.

A Little Later On, Share the Burden

The responsibility of being the parent of a child with PWS can be overwhelming at times. What you, the grandparent, can do to help may vary based on geographic location, job constraints, physical restrictions, financial issues and other factors.

Some grandparents are able to provide temporary relief by taking their grandchild who has PWS for a few hours or a few days; some grandparents may be in a position to care for the sibling(s) of that grandchild, giving mom and dad the ability to focus time, energy and attention on the child with PWS; some grandparents may have the ability to take all the children to give mom and dad a chance to be alone with each other.

When your grandchild who has PWS is in your care, it is very important that the guidelines established by his or her parents are followed. You may need to feed this child a special diet, lock up food, or give medication. The schedules and diet that mom and dad have set for the child should ALWAYS be followed. There is no room for "Just this one time." Structure and continuity of care are critical to your grandchild's health and well-being.

Arm Yourself With Knowledge

Becoming familiar with the syndrome is most beneficial at any stage, but the earlier the better. You and your entire family will need to learn all they can about the syndrome. Since PWS is quite rare, the grandchild's doctor may or may not have the most current information that you will need. The best place to get information that is accurate and current is the Prader-Willi Syndrome Association (USA). The PWSA (USA) website, www.pwsausa.org, has many valuable resources for you to print or download for your own information, or to share with family members or providers.

The Internet, libraries and bookstores may have resources for determined, inquisitive grandparents and parents, but keep in mind that PWS research is a continuous process, and is forever changing. What was considered fact yesterday, may be outdated today. View all information objectively and through an eye of caution. Many grandparents today are computer literate and enjoy surfing the Web - just remember, not all the information you find online is accurate.

A quote from a grandparent: "I was collecting information from the Internet shortly after my grandchild was diagnosed, and found an article that stated that PWS shortens the life of a child. It said many don't make it to their twentieth birthday! Now I know that this is NOT true. Many people with PWS live long lives with proper diet and supervision. Be objective!"

Learn About Diet

Your grandchild will likely need to follow a controlled diet plan throughout their lifetime. Talk to your grandchild's parents about appropriate mealtime foods and snacks, serving sizes, and meal or snack-time schedules. Read labels on all foods, and choose items that are appropriate to the diet plan that your grandchild is following. Learn to maximize nutrition, while keeping serving sizes and restricted items such as sugar or fat within set guidelines. Remember - ALWAYS follow the diet and schedules that mom and dad have set for your grandchild. No Exceptions!



Grandma and Emily Howard



Grandpa and Victoria Carter



Grandma and Jojo Ebrahimi

Take Your Grandchild to Appointments

Your grandchild needs to be seen by many different health care professionals. If it is comfortable for you and your family is in agreement, take the child to some of these appointments. Take notes, or consider recording the appointment (most modern cell phones have a "record" feature) to make sure mom and dad get all the information. You will learn a lot from these encounters, and it will take some of the wear and tear off mom and dad.

A quote from a grandparent: "I took my granddaughter to Cleveland for a three-day research study. I taped the conversations with various research personnel for my daughter to hear later. It was very rewarding to be with her for those three days."

Help Financially

Some grandparents are in a position to help financially. It is very important to provide that financial assistance in accordance with state and federal laws. Setting up a savings account in your grandchild's name may later prevent that child from receiving vital financial assistance from the state. Once the parents have consulted with a qualified financial advisor, they can let you know how your assistance can best be applied, and in what way they would like you to contribute. PWSA (USA) may be able to help you find specialized legal help for these situations.

Become an Advocate

When your family received the Prader-Willi syndrome diagnosis, it is likely that you had little, if any, knowledge about this disorder. Most people do not recognize the name, or know the effects it has on an individual. PWSA (USA) has many wonderful pamphlets and other materials aimed at providing information to various audiences including doctors, therapists, schools, and the general public. Collect them. Hand them out whenever possible. Many grandparents and parents use the brochure "Questions and Answers on Prader-Willi Syndrome" (available in the PWSA (USA) website online store) as an introduction to PWS. Research dollars follow recognized conditions. Your efforts can make PWS more recognizable!

And Speaking of Dollars, Hold a Fundraiser!

Grandparents can be very successful at fundraising and may have more time to do it than parents. PWSA (USA) depends on the funds that come in through these "grassroots" fundraising efforts; they play a major role in providing money for research, and to maintain the vital programs and services that provide daily support aimed at improving the lives and futures of your grandchildren! If you have an interest in becoming involved fundraising efforts, PWSA (USA) will not only provide you with ideas, but guide you through the entire process. Please call our toll free number, (800) 926-4797, to be connected with a fundraising specialist.

Being an Advocate Also Means You Educate Everyone

In our society, food is a big part of everyday life. Most people are still unfamiliar with Prader-Willi syndrome and the intense, uncontrollable drive for food that is characteristic of the disorder. They do not know the desperate measures your grandchildren may take to get the food they constantly crave. Therefore, your grandchildren need to be protected from the dangers that lack of knowledge creates. You and your family can help by educating everyone who has contact with your grandchild about the syndrome. Hopefully, as information about PWS spreads to greater numbers of people, fewer explanations will be necessary.

For now, it's better to avoid problems by telling others what your grandchildren need. For example, in restaurants, you could speak to the server privately; explain the child's dietary restrictions, and ask for smaller than normal portions if necessary. Ask that refills not be offered, and that the dessert tray or menu be withheld unless requested. If you have an informative pamphlet, give one to the server, and ask that they share the information with the rest of the staff. If you return to this restaurant again, you may find these steps less necessary.



Grandpa with Lacey Dunfee



Grandpa and Sandy Kay White

THIS IS YOUR GRANDCHILD

He or she will always be your grandchild. This syndrome has a wide spectrum of unique behaviors, and varying degrees of those behaviors. Not all children with PWS will have all of the characteristics. Thankfully, we have come a long way in the management of those issues which cause the greatest concern among families of children with PWS. Remember, Prader-Willi syndrome is what your grandchild has - it is not who he or she is!

HOW DO I HANDLE PROBLEMS DURING VISITS?

PWS-related behavior issues do not usually occur until the child is between two and four years of age. Many (non-PWS) children have behavior issues also, so how do you know what is "just being a terrible two" and what is driven by the syndrome? Well, you don't know. The good news is, the solutions are about the same. There are some excellent publications and videos available from PWSA (USA) that can help with behavior issues if needed. The important thing to remember is that everyone needs to have the same rules and expectations - and mom and dad are the Captains of this ship!

Seeking Food

Whether or not your grandchild is a food seeker, you will want to provide a food-free, safe environment for this child. Remove all candy dishes, put away all food-related objects, as well as cleaning products, alcohol and medicines. (A locked cabinet is the best place for those products). You may also have to provide a lock for your refrigerator. If food seeking issues develop, you must take the necessary precautions to provide food security for your grandchild.

Schedules

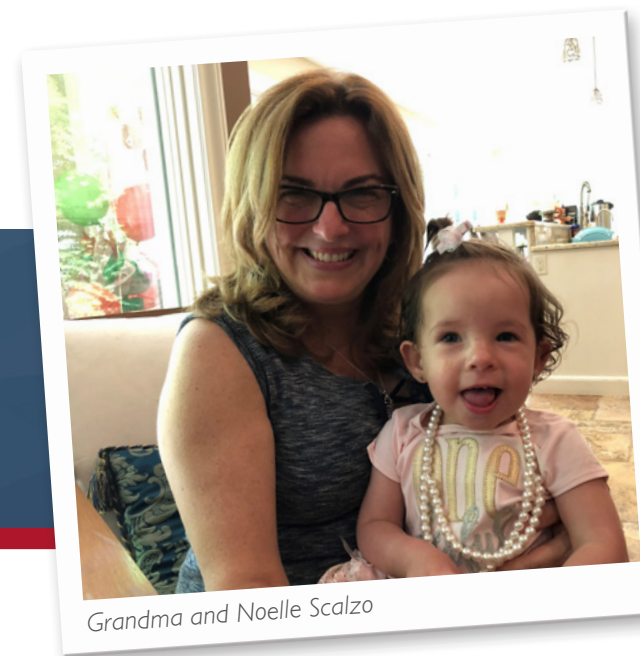
Routines tend to be very important to children with Prader-Willi syndrome. Promises should not be made unless you are certain you can follow through with them. Sooner or later a situation will arise that will require a plan to be adjusted. If a plan must be changed, try to give advance warning. Let the child be involved in making alternative arrangements. This will help distract them from becoming upset about what you originally planned to do.

Discipline

Most of the behaviors must be managed on a recurrent basis. Do not assume that once a child with PWS has been given a rule it will be remembered and applied. Punishments do not work for these children, and tend to make problems worse. Rewarding positive behavior is the best motivator, so remember: Praise, Praise, Praise!

Medical Alerts

Obtain a copy of the PWSA (USA) Medical Alert Booklet. Become familiar with any unique medical issue that applies to your grandchild. If you are a frequent caregiver, you may want a copy of your grandchild's personal medical information in case you need to make a trip to the hospital and/or the ER. If necessary, PWSA (USA) can provide crisis counseling or medical consultation with your grandchild's doctor.



Grandma and Noelle Scalzo

WHERE CAN I FIND MORE HELP?

Conferences and Workshops

Check the PWSA (USA) website at www.pwsausa.org for upcoming events. A National Convention is scheduled biennially, and typically occurs in the fall. State chapters may also have conferences, workshops, activities or events throughout the year. All of these programs can be a great source of encouragement and information. Medical professionals, caregivers, parents, friends, and relatives are welcome to attend these events. Encourage your family members to attend with you. If your child (the parent) cannot attend for some reason, maybe you could go, and collect the information for them.

Support Groups

While Prader-Willi syndrome is rare, it is not so rare that you cannot find someone who has been touched by it. Support groups can be found locally, or online. Ask PWSA (USA), your local chapter or your local children's hospital if they know of support groups in your area. In the event that there is no local group or network, maybe you can be the one to get one started!

PWSA (USA) Grandparent Program

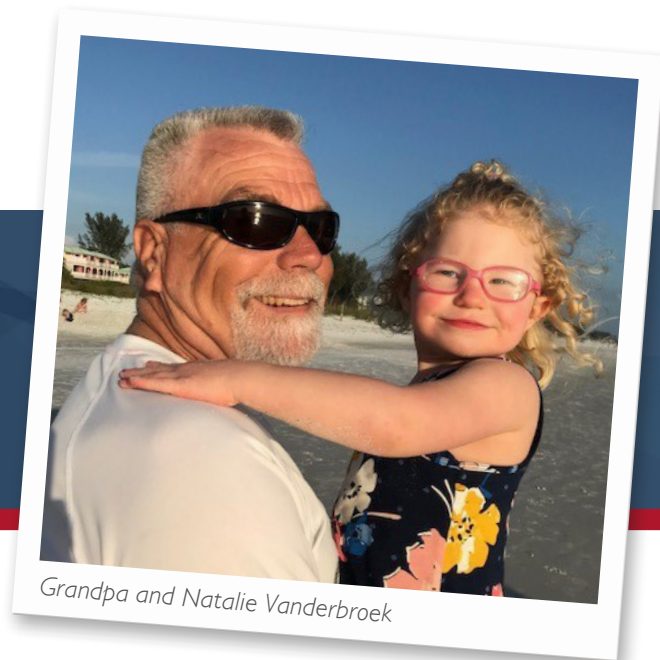
PWSA (USA) offers a support program for grandparents of children newly diagnosed with Prader-Willi syndrome. The goal of this program is to provide a friendly and confidential support network for grandparents from all areas of the country. PWSA (USA) offers a "Grandparents Package of Hope" which contains age-specific information about nutrition, growth hormone, physical therapy and more. You may also find the PWSA (USA) online support group for grandparents on Facebook at <https://www.facebook.com/groups/PWSAUSA.Grandparents/>.



Grandpa and Jojo Ebrahimi



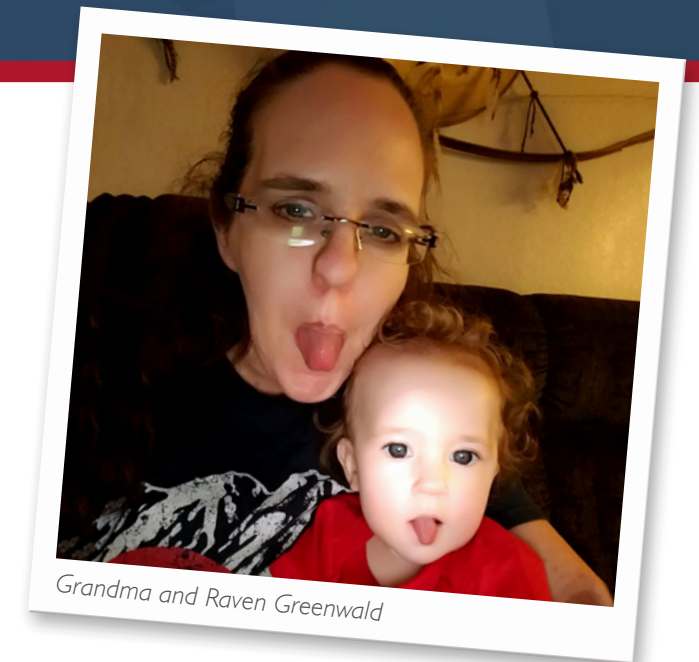
Grandpa and Isla Selinger



Grandpa and Natalie Vanderbroek



Grandpa with Hudson Petrie



Grandma and Raven Greenwald

A FINAL WORD

We have shared with you suggestions from some of our grandparents, but we are giving the last word to a parent who has served PWSA (USA) in many capacities, for many years. She writes this letter about “How You Can Help.”

“I have written the following letter for you to share with your family members and friends so they may have a better understanding of the help that we as parents need to support us and our precious children.”

For those of you who are helping a family member, we thank you from the bottom of our hearts.

For those of you who may not understand our need for your support, let me try to explain. I never really completely understood the magnitude of an old African proverb that states “it takes a village to raise a child” until I had a child with Prader-Willi syndrome. Our “village” includes an array of doctors, therapists, school personnel, PWSA (USA), etc. We need everyone to be in our PWS village if we are to make a difference in the lives of our beloved children. We need support and understanding, a shoulder to cry on, a quiet walk, or a promise of hope.

We understand that it is sometimes hard to know what to say or do; that maybe you might feel a bit awkward or afraid that you might say too much, or not enough. You might even be going through your own grief for our precious child and their parents.”

Here are some words you could say:

- “I don’t know what to say, but I want you to know I’m here to help.”
- “I don’t understand what you are feeling because I’ve never dealt with this, so please tell me if you feel I’m being insensitive or I don’t understand.”
- “I understand your time is limited, so tell me if I can be a caregiver so you can have some alone time, or if I can grocery shop for you.”

Here are some things you could do:

- Ask the parents if they would like you to host a family education get-together, inviting friends and family members over to learn and talk about the syndrome, ask questions, and find ways to help parents.
- Send cards, and keep calling, even if the parent does not respond. Often their lives are incredibly busy because of the child’s needs. Let them know you care without any strings attached.
- Be respectful and understanding of the PWS family rules. They might seem too strict to you - or not strict enough - but these rules are in place to allow the child to be healthy and to alleviate behavioral issues.
- Please don’t leave food out if a child with PWS will be visiting - especially during busy times like the holidays.
- Volunteer to be a “watch person” in half hour or one hour shifts to ensure the child doesn’t get unauthorized food. When your shift is over, clearly identify the next “watch person.”
- If you can’t (or won’t) modify your gatherings, please tell the parents so they know not to bring the child with PWS to your home.
- If the child has a behavior issue, please let the parents handle it.

I am often asked whether I would take this syndrome away from my child if I could. Absolutely, without a doubt! Would I be giving up her sweetness and innocence? Maybe, but I would also be taking away the hunger that haunts my precious child every minute of every day.

Many parents just live day-to-day, trying to cope with caring for their child’s needs, and do not have time to be involved in research or organization activities. If you are wondering what else you can do to help, please talk to the parents and let them know you are there for them. PWSA (USA) also has many aunts, uncles, and grandparents who are helping by serving on boards or committees, serving as officers, or having successful fundraisers. Please consider calling PWSA (USA) about these opportunities, or for information about becoming a member, offering support, or giving a monetary gift.

There are many ways to become part of our “PWS Village.” We look forward to hearing from you. Many thanks.

*Hugs,
 Carolyn Loker, mom to precious Anna.*

LIVING IN THE MOMENT

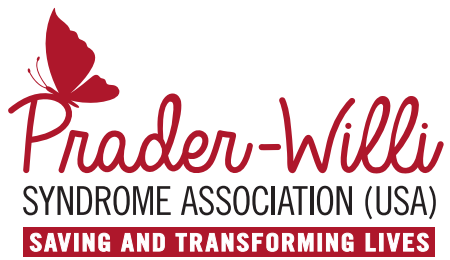
Try not to think too far into the future. No one knows what our tomorrow holds. None of our children come with guarantees. It is normal to grieve for the life you assumed you would share with your children and grandchildren. Life may not be what you thought it would be, but there will be many moments and occasions to enjoy. “Different” does not always mean bad. You will take pleasure in the little joys that so many take for granted. Appreciate all that your grandchild is, and rejoice in his or her successes. Though the road may be bumpy at times, your grandchild is a source of great love and joy for you and your family. Love them, let them love you, and savor every moment.



Grandpa and Natalie VanderBroek



Grandma and JoJo Ebrahimi



As always, **THANK YOU**
very much for your
involvement and support!

Prader-Willi Syndrome Association (USA) is an organization whose mission is to enhance the quality of life of those affected by PWS.

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