THE IMPORTANT ROLE OF PARENT ORGANISATIONS TO FOLLOW PATIENTS AFFECTED BY RARE DISEASES "I am not handicapped, i am special"

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ONE DAY DANIELE TOLD ME: "DAD, I'M NOT HANDICAPPED, 'CAUSE I'M NOT IN A WHEEL CHAIR, I SEE, I TALK, I WALK, I EAT, I HAVE FRIENDS, I ENJOY LIFE AND LOVE THIS WORLD....
IT IS TRUE, I'M DIFFERENT, BECAUSE I HAVE SOMETHING MORE YOU HAVE NOT...
I HAVE PRADER-WILLI SYNDROME, SO .... I AM SPECIAL!"

GOD BLESS OUR SPECIAL CHILDREN!

Our son Daniele was born in 1976 at the hospital in Feltre, a small town near Belluno in Northern Italy where we lived. We immediately realized there was something wrong with him and had to rush him to the hospital in Belluno because he had breathing problems. Pediatricians told us he could not survive and suggested he was baptized there and told us he probably had something bad to his brain. Although he was just two months old, they made a dangerous lumbar puncture with no evidence to any problem to the brain. We were desperate and decided to go back to the hospital where he was born and the head pediatrician there just holding him in his hands told us: "Your son has Prader Willi Syndrome" (PINS). In 1976 few Italian doctors knew this syndrome and could make a clinical diagnosis as he made. We were really lucky, because this doctor had a severely handicapped daughter and took her to the Children Hospital in Zurich (Switzerland) to be examined by Doctor Andreas Prader. While he was there, Dr. Prader informed him about the syndrome he discovered.

Why do I start my article with this personal story? The reason is connected to the purpose of this article headed to doctors and professionals following children affected by rare diseases, like PWS. When the doctor made the clinical diagnosis to my son Daniele he told me: "As you know English well, you can have a look at the description of the syndrome I have here for you". It was just a page but what was written there was scaring and terrible, saying we had to live a hell of a life and scientific literature reported 14 years as a maximum life expectation. My wife Maurizia and I looked at Daniele's eyes and said it was not possible and decided to face the situation our way as parents... Daniele is 39 years old today, he is working happily inside sheltered workshops after he worked 10 years in a regular factory. He lives with us at home and he is part of our community in the village where we live.

Doctors and scientists should remember that whatever they publish on a rare disease, which can be accessible to parents especially on the net, can be read by parents of children affected by that particular rare disease. Not all of them can react in a positive way as we did. We learned that LOVE can be

Daniele de padrino.

stronger and more powerful than scientific literature. It is the only remedy that has no contraindications because the more you give, the more you get. Doctors reading my article have not to feel offended because of that, but they should understand why both roles are fundamental to fight against rare diseases. Most parents learn a lot about scientific aspects of the disease affecting their children and become a little doctors themselves. We wish doctors fighting by our side to learn to become a little parents of special children too. This is the basis and the wonderful choice the International Prader Willi Syndrome Organisation (IPWSO) made since it was funded in 1991. We are a parent organisation of course, but wide open to the cooperation with professionals following PWS in the world and that's why we have one parent delegate and one
professional delegate in each member country belonging to our organisation.

Prader-Willi syndrome (PWS) is the most common known genetic cause of life-threatening obesity in children. The incidence rate of PWS is estimated to be one in 12,000 to 15,000. It is a complex genetic disorder related to problems along chromosome 15. The genes lacking in people with PWS have a major role in the regulation of appetite and metabolic levels, cognitive functions and behaviour patterns. PWS causes organic damage to the hypothalamus in the brain. This damage is irreversible. Historically, treatments with pharmacotherapy, surgery or behaviour modification techniques to abate the hunger have not been effective. The two hallmark characteristics of Prader-Willy syndrome are:

- Chronic, insatiable drive to eat
- Reduced energy output due to reduced muscle mass and muscle tone

These two factors can lead to excessive eating and life threatening obesity. In addition, the genetic condition typically causes cognitive disabilities, incomplete sexual development and problem behaviours.

THE INFANT is typically born with very weak muscle tone and experiences "failure to thrive". In some countries failure to thrive can claim an infant's life, since most infants cannot breast feed and have difficulty taking food from a bottle. Tube feeding is often required for several weeks or even months.
Respiratory problems may require monitoring and oxygen therapy.

THE TODDLER requires occupational, physical and speech therapies. At two to four years of age a child with the syndrome typically begins to develop an insatiable appetite. Unless some type of significant managements interventions is provided, the child will become extremely obese.

THE ADOLESCENT without appropriate management may develop extreme obesity, often leading to life threatening health problems and social ridicule. Kitchens typically need to be locked tight and guarded with vigilance. Equally significant are the emotional issues that arise, particularly as the child ages into adolescence and wants to have more independence than is possible to allow.

THE ADULT typically is unable to live an independent life, largely due to a lack of appetite control and behavioural problems. Social life is limited due to the need for a lifetime of controlled environments and activities.

Thanks to the support of IPWSO, many countries now have early diagnosis, more education for parents and professionals, growth hormone therapy (not approved yet in many countries) and medical assistance. Many people who have PWS are now living longer, healthier and happier lives. Research is ongoing to develop better treatments and discover the cause of PWS.

I would like to give you some examples of what parents organisations can do and achieve, starting with my personal story and how I was involved with IPWSO together with my family. Once we found out what syndrome was affecting our son Daniele we tried to know more about and contacted other families involved. We joined the Italian PWS Association based in Milano and they asked me to become their representative at International Meetings because of my knowledge of foreign languages and my business experience abroad. My wife Maurizia pushed me to do it because she told me we had been lucky having an early diagnosis and we had to help other people that had not the same opportunity. When I joined the 2nd International Prader Willi Syndrome Conference in Oslo in 1995 I realised how other developed countries were organised. I represented the Latin World together with a father from Spain and a mother from Argentina and the first impression was we lived in another planet. I was invited to be part of the new IPWSO Board where I have been asked to follow public relations and then I became also treasurer of the organisation. In 1998 I organised the following International PWS Conference in Jesolo near Venice (Italy) and was elected as IPWSO President. We had 21 member countries then, mainly from Europe, Northern America, Australia and New Zealand. Latin America was represented only by Argentina, Africa was represented by South Africa and Asia by Japan only. My first objective as President was to expand our contacts and spread our voice around the world, starting with Latin America with the precious help of the PWS Association in the United States that gave me all contacts they had.

Today we are represented in 103 countries and cover almost all Latin America. We were lucky meeting brave parents and good doctors that joined our organisation and helped us a lot building our network. In some countries we were lucky to get in touch with parents who are also physicians and could help us a

lot in creating awareness and get their associations organised the best way. We have parents who are also doctors or professionals involved with PWS in China, Cuba, Egypt, Denmark, Hong Kong and Qatar. In many countries we started with a parent, especially mothers, who decided to take the lead and start talking about PWS, as it happened with Chile.

In 1999 a mother from Arica contacted me by email saying she suspected her daughter had Prader Willi syndrome and she asked me information about. I gave her all information I had in Spanish and translated other documents from English I thought to be interesting. Once she got these information she contacted the national TV and decided to go to Santiago to participate to a talk show to explain what PWS was using all information she got from me. Soon after many cases arose and the first cell of the Chilean PWS Association was formed. In 2002 IPWSO organised the 2nd PWS Latin America Conference in Chile in close cooperation with the local association and I asked organisers to contact that mother in Arica and invite her to join us because I wanted to know her personally. She came with her daughter and we had a very touching meeting together. She asked Dr. Suzanne Cassidy, who was key speaker in Santiago, to visit her daughter and she was told her daughter had not Prader Willi Syndrome. I can't forget this courageous mother who did so much for PWS in Chile and then discovered her daughter had something else. My friend Dr. Fanny Cortes was there and she will remember the case. I do hope this girl was diagnosed and this mother had the opportunity to follow her properly. This is just a first case I wanted to report as an example because you are from Chile and must realise what parents can do. I always say: "PARENTS CAN MOVE THE MOUNTAINS".

When I became IPWSO President in 1998 we had very little money available as we could count on our subscription fees only and had no access to pharmaceutical companies sponsorship yet. I used my frequent travelling around the world for business and also for my music activities and concerts to visit hospitals and especially to meet parents I had the opportunity to get in touch with via email. In 1999 I had a tour of concerts in Uruguay and Argentina so I could meet parents in both countries for the first time. In Montevideo I met 9 desperate mothers, because their husbands abandoned them soon after the diagnosis of their child was confirmed. This is unfortunately a common story I came across in many countries in the world. I listened to this group of mother for over 6 hours because they needed to discharge the heavy load they were carrying for years in their hearts. At the end they thanked me for my visit, not only as IPWSO President, but also as a man whom they could trust again. Today Uruguay has one of the most organised PWS Associations all over Latin America, but everything started that day when scared, shy and worried mothers became leaders and knew they were no more alone. "PARENTS CAN MOVE THE MOUNTAINS".

In 2002, thanks to the generosity of some Italian parents, we organised the 1st IPWSO Delegates Meeting at BIRD (Italy) in April 2002 with 90 participants from 44 different countries. A milestone in IPWSO history. Here below you can read what a mother from Guatemala wrote about this experience:

We are a family from Guatemala with 5 people. Two girls and a boy, who is our second child, who is affected by Prader Willi Syndrome. His name is Luis Javier Barrios Urizar and we have been to BIRD in Italy in the year 2002. Following our participation to this Meeting we achieved as follows:

1. Real and true information about PWS
2. Information that can give us real life expectations for our child
3. Information needed to offer a better quality life to our child
4. Information about what problems we can face if we do not follow the guidelines and do not take care of him
5. Information about diet to obtain an acceptable weight control level
6. Information about the psychological therapy needed for the whole family
7. Information about behaviour disorders we might face
8. Information about the existence of different drugs to help facing various negative aspects of the syndrome
9. Information about the existence of a large International family where everyone can offer his own personal support and experience to new families having a baby with PWS
10. To know and meet the best specialists in the world about PWS and have the possibility to talk and write to them.

The delegates meeting at BIRD in Italy changed our lives. Living in a poor undeveloped country in Latin America we were not educated and could not afford to travel so far. In our country there are no schools or Institutes that take care of children with this kind of disease, so once we got all the information we needed we parents created our own support group to educate and follow our children at home and we do our best to facilitate the possibility for our children to live in our society, which is not ready now to accept disabled people. Our life changed completely thanks to the information we got from IPWSO and through the precious sharing we had with other associations in the world. We have to say that we feel stronger and safe to belong to such an International group where we help each other and where we are continuously updated about research and new drugs that can help our children.
A great service we achieved was the free methylation test at BIRD which gave us the possibility to send blood samples of three more children and have a negative answer, so we could investigate in other directions.

Mayra Urízar
Luis Javier mother

BIRD 2002.

In 2002 I had a first contact with Dorica Dan, a scared shy mother from Zalau in Romania who asked for help. In 2003 we welcomed her in Italy and started cooperation with Romania she was willing to represent. Her daughter Oana was the first patient with PWS diagnosed for free at the Genetic Molecular Laboratory at BIRD in Italy where IPWSO office is located. Since then, this strong mother turned into a tiger and became a determined leader, not only in her own country, but also internationally. She organised together with IPWSO the 6th International PWS Conference in Cluj Napoca (Romania) and today she is Vice President of Eurordis. "PARENTS CAN MOVE THE MOUNTAINS".

With an incidence rate estimated to be one in 12,000 to 15,000 you can imagine how many cases of PWS can exist in large countries like China and India. In 2008 I travelled to Mumbai (India) to attend APPES, an International Endocrinology Congress, with an educational booth to inform doctors about the syndrome. While there, I visited an important paediatric hospital where I met a famous professor head of the paediatric department of this institution. He was surrounded by many young doctors who were clearly afraid of him and he was quite impolite and rude to me knowing the purpose of my visit because a parent dared to talk about scientific matters. When I started describing the Prader Willi Syndrome, he stopped me and said: "This is a western disease, no cases exist in India". Then I asked the Indian parents who accompanied me to give me the pictures they had of various patients with PWS from all over the country. His reaction was furious and he turned away sending me to the hell... I can't forget the thankful glance and admiration I saw in the eyes of the group of doctors following this person. This is a common situation we are facing in many countries when approaching some professionals, especially where a diagnosis is not possible to be made in their laboratory facilities. Our information booth was run by two young parents from India as you can see on the picture and many doctors called by. In 2009 Prof. Suzanne Cassidy and myself travelled back to India and this time to Bangalore in the South to participate to a General Paediatric Congress again with an information booth where over 10,000 doctors attended from all over India. We were invited by Prof. Palany Raghupathy a senior paediatrician who introduced us to this important meeting and opened many important doors to IPWSO. Shikha, a young mother bravely took the lead of a National PWS Association and she keeps fighting for all children affected in her country like a real tiger. "PARENTS CAN MOVE THE MOUNTAINS".

On January 21st, 2015 we received great news from Dr. Raghupathy:

Dear Giorgio and Shikha,
Greetings from Bangalore!

Shikha will remember that in the last PWS Parent Group Meeting which I organized here in Bangalore during May last year, I had promised the parents who attended that I shall arrange for regular checkup and follow up monitoring for these children periodically, during which time, the parents would be able to consult all the specialist consultants on the same day under one roof. Somehow, I was unable to commence this service last year.

I am now pleased to inform you that I have made a beginning now in the new year and we inaugurated the first ***PWS Polyclinic Service*** *on 25th January 2015. We had 9 Paediatric and Adolescent specialists in the Clinic, viz., Endocrinologist, Clinical Geneticist, Surgeon, ENT surgeon, Gastroenterologist, Developmental Neurologist, Nutritionist / dietitian, Physiotherapist, and Occupational therapist were available for individual consultations. The parents expressed their appreciation in seeing all the specialists in one sitting and especially those who travelled from places other than Bangalore found it very convenient and time saving to get their medical advices from all the consultants on a single day. Twelve families registered for the Clinic this time but only five families attended, while the others expressed regret for their inability to attend for reasons beyond their control.*

Mumbai 2008.

I am planning to have such Clinics here once in 4 months and the next Clinic will be on 1 May 2015.

This is for your information. With kind regards,
Yours sincerely,
P. Raghupathy

In 2012 I participated to the first PWS Workshop at La Habana in Cuba in May IPWSO organised in cooperation with Caritas (Vatican). Everything started 3 years ago when a doctor from Cuba, whose name is Loisel Bello, contacted IPWSO through his brother in law who lives in Sweden. He wrote to me saying he needed help to confirm the clinical diagnosis made to his 4 years old daughter Gabriela, as this was not possible to be done in Cuba. The methylation test confirmed the diagnosis and that Gabriela had PWS caused by UPD. Loisel immediately asked for information and educational material in Spanish we provided and expressed the wish to participate to a PWS Scientific Conference somewhere in Europe to learn more. We invited him to join the International PWS Conference in Taiwan in May 2010 instead and covered all his travel costs, while Cuban authorities and especially the Ministry of Health of his country helped him a lot to get the passport and the permission to leave Cuba. As soon as he returned home, so enthusiastic and full of information, he organised a 1st workshop for professionals and parents in his own town, hosted in a room of Caritas, as this Catholic organisation is very active in assisting disabled people throughout the country. Loisel is married to Marlen, a charming young lady who is psychologist specialised in teaching children with disabilities. We were so lucky to have a young family as a reference in Cuba where both parents are also professionals. They accepted to represent IPWSO and so Cuba became a member of our International Organisation. They asked Caritas to help them finding cases throughout the country, spreading the voice to their branches connected with the various parish churches. In a short time they found 15 patients and especially many doctors and professionals interested to know more about this syndrome. Once Caritas offered to host a National Workshop open to professionals and parents and to help families financially to join La Habana, Loisel contacted me to achieve the participation of important speakers in Spanish language from Latin America and Europe. The key speakers I contacted accepted my invitation with enthusiasm and covered their own travel expenses. The speakers are: Dr. Moris Angulo (El Salvador-U.S.A.), Dr. Maria Del Valle Torrado, Dr. Hugo Serdloff, Karina Abraldes (Argentina), Irune Achutegui (Spain-Italy), Dra. Fanny Cortes (Chile). They covered all important aspects of the syndrome such as genetics, endocrinology, paediatrics, psychology and psychiatrics.

Local parents appreciated also the presence of parents coming from other Spanish speaking countries representing IPWSO network: Luis Barrios and Mayra Urizar from Guatemala, Julia Bonelly from Dominican Republic, Fernando Briones and Mariona from Spain and Giorgio Fornasier from Italy. All scientific speakers modified their own presentations to be understandable by parents and this was highly appreciated by Cuban professionals too, because they learned how to approach parents with scientific and medical issues in an easiest way. The priority was given to parents, to their questions and especially sharing experiences. During breaks and meals local doctors had the opportunity to talk about scientific details with foreign speakers directly.

The 2nd Workshop on Prader Willi Syndrome in Cuba was held from 27 until 29 April 2012 at the Sacaerdotal House in the Capital La Habana, under the precious umbrella and organisation of Caritas Cuba. We all slept at the same house where the Conference was held and had meals at its restaurant, so we had plenty of time to stay together till late at night. The meeting room had equipment for video presentation and became more a sort of a family sitting room, than a Congress. Looking at the audience, you could not distinguish who were parents and who were professionals. They all participated by heart, laughed and cried together. It was amazing to realise that 3 years ago there was almost no knowledge about PWS in Cuba and now we had 63 people attending the workshop so divided:

6 professionals from abroad
32 professionals from Cuba
6 parents from abroad
15 parents from Cuba
4 volunteers of Caritas Cuba

We can proudly show in the attached picture the smiling group that participated to the Workshop and among them there were parents who were visiting La Habana for the first time and they did not know each other. We all cried listening to the mother of Manolito, a 19 years old boy who died some months before. Manolito's mother came to honour the memory of his son with her presence and participated to the discussion and sharing. At the end she told everybody: "Dont' miss the unique and precious

Cuba 2012.

opportunity you had and what you learned at this fantastic meeting. Work hard and let other Cuban children with PWS live!"
In October 2013 I organised a Meeting called "Convivencia" for families with children affected by PWS in Cuba in cooperation with Caritas. I personally raised funds for a two years project through a tour of concerts I made in Rome in close cooperation with Caritas at the Vatican.

Cuba is a big Island 1.200 km. long where 11 million people live, distributed in 14 different provinces. The majority of parents who participated to the 3 days "Convivencia" never travelled outside their own town or province, because they cannot afford and never stayed in a Hotel before.

In such a situation a Cuban family with a chid affected by Prader Willi Sindrome or any other particular rare disease is left alone to manage something they ignore without any guidelines and information about the disease and what the future will bring. Difficulties to contact other families not having access to any communication system common in our countries increased their frustration and loneliness. For this reason we planned a special meeting for them in Ciego de Ávila called "Convivencia" from 18 until 20 October 2013 with all families hosted in a Motel located in a nice area outside the town they achieved from the local Government Office. We had an incredible participation in spite of all communication and public transport problems and must thank Caritas for their network of churches covering the whole island. 22 people with PWS from 4 until 34 years old participated with their families coming from all Cuba territory. In total we had 64 people as families, plus volunteers and caregivers for a total of over 90 persons involved. The meeting started on October the 18th in the morning with a very difficult and brave action as we separated parents from their own children, which never happened before. Parents were really worried and suffered a lot for that, while it was much easier for the kids. Mariona Nadal from Spain took care of them and coordinated the whole program at the Zoo together with caregivers and volunteers she properly instructed how to manage people with PWS. Everything went well without any significant problem or crisis and they had to send messages by mobile phone quite often to people following parents to keep them calm and tell them not to worry about.

Parents immediately felt at ease and realised they had at last the opportunity to achieve answers to questions they accumulated for years. Sometimes we had to stop people's outburst and talking and let them often cry freely, as if a big glacier was melting. They did appreciate our presence as a family coming from the other side of the ocean with the oldest child of the group asking so many questions about our experience in managing Daniele and having also the possibility to ask him questions directly. I would like to end this report to the Board translating from Spanish an email sent to Moris Angulo by a doctor in Cuba the day before I left Italy.

This is the proof of what achievements we can have when IPWSO succeeds in organising parents and professionals in a country:

Hi doctor! How are you? It's a long time I have not your news.
I wish to inform you about something that made me very happy.
The Director of Health and Care in my province called me yesterday to tell me they accepted my request to attend and follow children with PWS. My patients have more than 20 years, so I was unable to follow them at the hospital, being a paediatrician.
From now on I am allowed by the Government to attend them and cure them at the Paediatric Hospital where I work, any time they need, independently from their age!!
This permission allows me to continue being their own doctor.
Moreover they can achieve food at a favourable price even if they are more than 18 years old. The good thing is that any other children with PWS in Cuba can have the same treatment entering my hospital. A good news at last!!

I know Loisel is gathering parents and children with PWS in these days, but I am sorry I cannot join them. Anyhow, this is another dream come true!
Take care
Julieta

"PARENTS CAN REALLY MOVE THE MOUNTAINS"
I would like to end my article with our personal stories and experience, having a son with PWS who is an adult.

THE THERAPY OF LOVE

Our son Daniele is 39 years old today. After he finished his studies at a professional school, he worked successfully in a couple of factories for over 11 years and was happy to live a life that looked normal to him. Two years ago, all of a sudden something changed dramatically and we think someone at work offended him saying he was a disabled boy without a future. He probably opened his eyes on a different reality and realized he was nearly 30 years old, most of his schoolmates were driving a car, had their own apartment and were married with children... He had nothing instead and no hope or expectations to have it in the future! He fell into a depression, left his job and kept crying all day long. Facing this crisis, we felt lost and desperate and took him to a specialized Hospital in Milano. For the first time in his life he had to take psychotropic drugs to overcome his paranoiac obsession and after a few months he forgot about his Spanish identity and was Daniele again. But he was no more the lovely, cheerful and caring boy we knew and we had to accept this change and a new reality.

To worsen the situation ten months ago his brother Redi, who is only one year older, became father of a beautiful boy whose name is Alessio. You can imagine how happy we were, but Daniele wasn't and strongly refused to be called as a uncle and did not

recognize him as his nephew. Psychologists at the Hospital said he was jealous, but this was not the case. Our children with PWS are not stupid, they have a simple but clear and precise logic that we "normal people" often do not realize. To recognize Alessio as his nephew was the same as admitting his defeat and to be different with no hope to be a father himself too. I took Daniele with me to Brazil last February to offer my wife a period of relief, as I was leading a group of 40 tourists to visit the South of this Country where a large population of Italian origin lives. At the end of our program we visited Bairro da Juventude, an Institute run by an Italian Priest, Father Vincenzo Lumetta, who takes care of over 1,500 children who live in the poor and degraded outskirts of a town in Santa Caterina State. Children who have not enough to eat or have not enough clothes and often suffer any kind of violence. Children who can have a future only in this house where they can find love, food, clean clothes and especially a good professional education, so they can get a job when they finish the internal school. As I am personally involved in helping this mission to support these children with individual sponsoring of Italian families that we call "distance adoption", I always take people I lead on tours there, as they usually adopt many children and provide the money they need to be properly followed and continue their studies. I was too busy to follow my group of 40 persons and I did not realize that my son Daniele chose a boy and a girl, took a form and filled it completely with all data to become their "father". While I was in the office together with Father Vincenzo and had just made my annual donation to the Institute, the door opened and a shiny Daniele came in holding a boy and a girl by hand. He was excited, but at the same time he was afraid of my reaction, as he did something important without my permission. He first looked at me and then said: "Father Vincenzo, I adopted these two children!". Father Vincenzo who knew about Daniele's crisis smiled and said: "They are yours! Your father just paid one year fee for both."

I will never forget the gratitude and happiness in my son's eyes. He gave me a long strong hug and then introduced me to my new grandchildren João Pedro and Ana Alice. Then Daniele asked me to give him my mobile phone. He phoned my wife first and said: "Mom, I made you Grandma twice!", then he phoned his brother and proudly said: "Now you're uncle too!" and then he said the key magic words that made me cry and understand the nightmare was over: "How is my nephew Alessio?".

A few days later I brought a new Daniele back home, the happy smiling boy we knew, more mature and more careful now. He was no more a child, but the responsible father of João Pedro and Ana Alice. Since then our life has changed and our son Daniele is a wonderful uncle to Alessio and went back to work as a volunteer guard at the local Municipality. He always talks about his children and proudly shows their pictures to everybody he meets, as all "normal" parents do. He writes to them quite often and they answer to him and have exchange of drawings they make, hoping they will be connected soon by Skype, so they can talk directly and see each other on webcam. Once again our son with PWS is surprising us. He found the way out alone and the perfect solution to his problems. He did not know the causes, but he realized he could not have biological children in his life, so he found the easiest way to get his own family anyway. His life has changed completely and everything is finalized to his international family, so he is taking care to save or earn the money he needs to pay the annual fees, he often writes emails or letters to them and get organized to send gifts or wishes for their birthdays or for Christmas. We are planning a trip to Brazil with Daniele every two years to see how our grandchildren are doing and this is really the best therapy we can offer our child and ourselves too... a therapy of love.

Daniele and their sons.

Long ago a mother from Venezuela asked my wife Maurizia which was the secret she had to raise our son Daniele so well. This was her answer:

Intuition
Good sense
Trusting
Love

Dear Alicia,
you are talking about a secret, which in reality does not exist, so I cannot reveal it to you.

Since Daniele was born 26 years ago when few doctors knew the syndrome in Italy we followed our **intuition** or parents' instinct. We had precious advices from doctors, of course, who told us which diet to follow and exercise but they were giving general suggestions about a disease they had not direct experience of. We took note of all advice we got but at the end we preferred to continue also our way. For this reason after the intuition we added

our **good sense** or sound judgement to be used in proportioning food and education to come to a correct behavior inside the family and the society around. We decided not to prohibit any food, but giving him always half a portion, punishing or rewarding him according to each situation. Then we gave him full **trusting** and Daniele knows well he must deserve it to keep it forever. We are leaving him alone at home for short periods during the day in our home where there are no locks and everything is open and available. Sometimes we ask him to cook our lunch or dinner, which is something he loves to do, picking up some ingredients from time to time as all cooks do, even though they have not PWS! We leave him plenty of time to do it because he likes listening to the radio while he is cooking and he is singing dreaming about his bright and happy future. When we reported the doctors belonging to the Italian PWS Association about the fact that Daniele studied at the Hotel School they told us we were fool and irresponsible parents because we had NEVER to leave a child with PWS alone in a kitchen. We did not make any miracle, but there is no doubt that we reduced the obsessive tension he had towards food, which turned from enemy into a friend.

We cannot say we achieved only positive results as his weight is not the ideal doctors suggest to reach, in theory. Daniele is 1,60 mt tall and at his age of 26 years his weight varies between 74 and 76 Kg. He should lower his weight of 7 extra Kilos to be in good form, but this could compromise the positive equilibrium and emotional balance we achieved. Daniele is a quiet boy without significant behavior problems, goes to work alone and within the village where we live.

Giorgio and I believe we must come to a compromise and accept a son who is fat (not obese) but happy, without turning his life and our life in a hell to reach theoretical results so he will hate the world he loves so much.

I have no other secrets as you call them, except a very important addition to what I wrote above... much **love**.
Hugs
Yours Maurizia

"PARENTS CAN REALLY MOVE THE MOUNTAINS" BUT WE COULD MOVE THEM BETTER AND FASTER IF PROFESSIONALS AND DOCTORS ARE HELPING US TO PUSH MORE!"

Many thanks

Giorgio Fornasier
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