



# DOLPHIN THERAPY FOR YARA

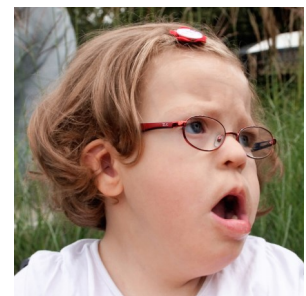
*To help Yara make a step forward*

Brochure

April 2017

## Who is Yara

Yara is a wonderful 8-year-old girl who suffers from Pal-  
lister Killian Syndrome, also known as PKS. This is a rare  
mosaic chromosome abnormality, which means that Yara  
is unable to walk or talk. Yara has a brother, Ramon 11  
years old, and a little sister, Isabel 5 years old, and of  
course her mother Sandra (45) and father Eric (46). They  
are a happy family in which Yara plays a leading role.



## Why this sponsorship folder

Through this sponsorship folder you can see who Yara is,  
learn more about PKS syndrome and why the family  
wants Yara to have Dolphin Therapy. You can also read  
about what you can do for the family.

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## Yara

### The Discovery

Yara was born on 27 April 2009 after a normal healthy pregnancy. She was slightly overweight at 3.9 kg (8.5 lbs) but of normal height of 52 cm (20 in). Immediately after birth she had to be kept warm and given extra oxygen. In the days that followed, Yara was very weak and was unable to feed, so she had to be fed intravenously through a nasogastric tube.

One of the paediatricians of the Scheper Ziekenhuis Emmen noted Yara's striking appearance. Her parents did not (or did not *want to*) know that anything was wrong. In spite of this, the doctor sent photographs to the University Medical Centre at Groningen, and Yara was transported to Groningen for more tests. The clinical geneticist knew by chance exactly what to look for, and on June 8 Yara's parents were given the devastating news that Yara has Pallister Killian Syndrome. The ground opened up beneath them ... this was so completely unexpected and was such a serious and rare syndrome.

### How are things now

Yara is now a bubbly 8-year-old girl. She receives weekly physiotherapy, and her parents and therapists work hard with Yara to boost and stimulate her development. The house is full of aids to support Yara when sitting and bathing, and to transport Yara so that she can lie down and sleep comfortably. She has her own custom-built bedroom and bathroom on the ground floor.

At present she is in reasonably good health. In the first couple of years of her life she suffered regularly with cystitis and urinary tract infections. Thankfully she does not suffer from epilepsy and her heart is doing well.

## PKS

For Yara, PKS means that she will always be dependent on others. She finds it hard to make contact, she has relatively weak muscles and her hearing is severely impaired. In addition to these difficulties she has impaired vision and a greater chance of epilepsy, heart problems, learning disabilities, developmental delay and a different physical appearance.

The syndrome was discovered by taking cheek swab and blood tests. If one knows where to look and what to look for, the abnormal chromosomes are found fairly quickly. Pallister-Killian mosaic syndrome is not inherited. The chromosomal change responsible for the disorder occurs as a random event during the formation of reproductive cells (eggs or sperm) in a parent of the affected individual.

For more information, please refer to the following sites:

<http://www.pkskids.net>

<http://www.pkskids.nl>





Although Yara's muscle weakness has improved, her body muscles are not strong enough to support her own weight, so she cannot sit independently and has severe problems with her balance. Yara is not able to pick up her own toys. If you put a toy in her hand, she can hold it for a few seconds, but she does not consciously play with it. More recently, Yara has developed the habit of wanting to touch your arm or head.

Yara also has problems with her vision. She wears glasses and has been diagnosed with CVI, which means that her eyes cannot focus on one thing, as there is a 'short circuit' when processing images. Yara's hearing is severely impaired, but she has hearing aids that help her to manage this at a reasonable level.

It is not easy to make contact with Yara, the people closest to her have learned to 'read' her instead. The problem is that Yara barely looks at you, but can only communicate through loud noises or crying. Her parents and carers use sign language in addition to talking to Yara much of the time.

At first, Yara became quickly over-stimulated and so slept much of the day. Now, she has a much more regular sleeping pattern, and her feeding has also improved. She has a Mickey Button on her stomach to which the feeding tube is attached for intravenous feeding, but she is also able to eat some solid or pureed food from a spoon. Her parents and carers give her this, as she is not able to feed herself.

Yara attends a day care centre for four days a week from 9:00 to 15:00 and also receives counselling for a few hours each week.

While all of this may sound serious, her parents and brother and sister are very close to Yara! She's an important part of the family. Whenever they get the chance to go out, they all go together. She has given the family so much, including some wonderful encounters with lovely people and a glimpse into a special world. It's too easy to dwell on the bad things and miss the small important things in life. Yara is a very happy girl, and when she shows her beautiful smile the sun breaks through and shines on the world around her!



## What is Dolphin Therapy?

Dolphin therapy is a scientifically proven form of integrated therapy: the centre offers a personalised programme tailor-made to each child's needs, focusing on developing the child's fine and gross motor skills, speech and language, cognitive development and social and functional life skills.

Dolphins play a vital role in the programme, they are very social and unconditionally accept children with special needs. Interactive contact with the dolphins not only acts as a reward and motivates the child to persevere with the exercises, but research has also shown that this interaction increases the child's concentration and sensory integration.

## The CDTC

The Curacao Dolphin Therapy Centre is a world-leading dolphin assisted therapy centre, founded in 2004 and located in Curacao. Their committed team consists of qualified and specially trained professionals such as psychologists, physiotherapists, speech therapists, occupational therapists and, of course, five bottlenose dolphins who are used exclusively for the therapeutic programme.

## Why It Works.

Contact and interaction with dolphins stimulates and rewards patients to progress. A dolphin can hold your attention, put you at ease and motivate you in unique ways. Following a two-week programme, patients have shown significant improvements that had previously seemed impossible.

For more information, please visit:  
[www.curacaodolphintherapy.com](http://www.curacaodolphintherapy.com)



## Dolphin Therapy for Yara

Yara's parents and therapists are passionate about giving Yara the opportunity to experience Dolphin Therapy. The hope is that Yara will make more progress in two weeks there than through years of regular therapy.

### Why now?

Health-wise, Yara is doing in better than ever. Because she is hardly ever ill, the focus can be put on her development. She has already shown some small signs of progress (a cursory look at a toy, holding on to a ball, etc). With the dolphin therapy she should be able to make leaps and bounds in her development.

One anticipated aspect of her development will be in the feeling in her mouth, so that she can learn to eat coarser food. Also dolphins, with the team, will teach her to focus and make a choice between two objects. Can they really teach Yara to hold on to a toy and play with it? Will Yara, with the dolphins' help, be more able to keep her head and body balanced? There are so many fun things for the team to work on!

Her parents are not hoping for a miracle, but it is a fact that many children with this therapy do experience a breakthrough. Sometimes they even learn things that no one thought they could ever learn!

The new insights and strategies that the family will take home from the Dolphin Therapy Centre will stay with them for years. With these new experiences and tools Yara can continue to make progress at home for a long time to come.

### Family involvement

Eric and Sandra will be intensively involved in Yara's therapy so that they can help their daughter to continue her development at home. They will also receive guidance and advice in the form of counselling from people who know what it's like to raise a disabled child. For Yara's little sister and older brother there is a special 'Brother And Sister' programme.

### Why Curaçao?

Why travel to Curacao rather than have therapy at the Dolphinarium in Harderwijk? Because therapy at the Dolphinarium is more focused on children with autism and Downs Syndrome. It does not offer the intensive therapy needed for Yara's multiple complex disabilities. In Curacao there is a whole team waiting for her, and the team will still be involved after Yara returns home to the Netherlands.

### Shared Experiences Of PKS Partners.

Parents of children with PKS have contact with other families all over the world and they are also heavily involved in the research into the Pallister Killian Syndrome by Dr. Krantz of the Children's Hospital of Philadelphia. The results of the dolphin therapy are shared with all involved to hopefully help more children with the same syndrome.







## Friends and experiences

### Fenna

Fenna, an eight-year-old girl with the same syndrome as Yara, went to Curaçao in 2014 to follow the same dolphin therapy. It was intense but also immensely enjoyable. Daily sensory integration therapy, games, exercises and course work sessions in the water with their permanent dolphin, Bonnie. What an experience!

Fenna's mum, Nathalie wrote in the travel diary: "Do we see any change?" it's a question that is asked a lot. Fenna is very cheerful; she's relaxed and clearly feels good about herself. She managed two breakthroughs completely unaided and, according to Merel, Fenna's therapist, the therapy has had a made a big difference to her oral skills. We have acquired great tools to practice with Fenna at home. Even months later we have noticed improvements in her. So, the therapy has had a long-lasting effect".

### Faya

Faya is a 9-year-old girl with Phelan-McDermid syndrome. She has undergone the dolphin therapy 3 times now in Curaçao, and her mum, Peggy, told about some of the great goals they achieved this year:

"Faya doesn't need a dummy or lace anymore. Those who know more a little about Faya and us, know that Faya has had a dummy all of her life. During the therapy they stimulated Faya's mouth area, and on Sunday February 7<sup>th</sup>, we all threw away her dummies, for good! From that moment on Faya began to get a good night's sleep without her dummy. There are times when she misses it during the day, and then she will look at us and suck on her t-shirt, especially if she is bored. We just tell her she is not allowed to have it and try to distract her, and that seems to work.

We have learned certain skills to deal with Fara's behaviour. She often runs away and lies down on the ground if she doesn't understand or doesn't want to do something. At first, we weren't sure whether she was doing this to tell us something or whether she was being uncooperative. It turned out she wanted to be uncooperative. In Curacao, we focused on tackling this behaviour for two weeks. That doesn't mean that she has stopped doing it, she tries it on daily, but we now know that consistency really pays off, so we just carry on regardless by either ignoring her, taking a time out, or by distracting her. Faya often uses the 'work' sign with everyone. We have now discovered (by observing her constantly) that she actually wants to know what other people are doing, so we tell her, and she seems fine with it. It is clear to see that once she is understood, Faya is much more at ease and less frustrated. All in all, she has learned a lot, but still has much more to work on. It's so nice to see Faya improving and to know there is still even more possible."

## Sponsors wanted

### Donations

Unfortunately, Dolphin therapy is not covered by health insurance. This means that the family must raise the total cost of 20,000 euros themselves. However, given their current circumstances, this is impossible.

When Yara was born, Sandra had to stop working because the care was too complex. The additional costs that are inevitable with a disabled child are only just bearable. That's why Eric and Sandra are looking for sponsors.

If everyone makes a small contribution, then perhaps within a year, Yara will be able to make huge steps in her improvement. This would dramatically improve her quality of life, something she would be able to take away with her and that would stay with her for the rest of her life!

Any contributions can be transferred to the following Bank Account:

**IBAN: NL20RABO0152965300 - Y. Snippe, Sleen**

**BIC: RABONL2U**

Or through Paypal: [info@dolfijntherapievooryara.nl](mailto:info@dolfijntherapievooryara.nl)

### Auction

Yara's parents would like to organize an auction. They hope to do this in cooperation with the famous auction site, BVA Auctions. Firstly, they want to write to the major sports teams in the Netherlands asking them to donate an autographed auction piece for Yara. But they need your help. Do you have contacts or do you have an interesting auction item that you can donate for people to bid on? If so, can you please contact Eric and Sandra?

### Events

If you also want to support Yara and become a sponsor by organising a sale or other event that would be fantastic! The family will be happy to provide flyers. If it helps, it is also possible for Yara and her parents to attend the event and talk about their experiences with Yara.

### Registration

The name, logo and website of your company, school or organization will be listed on [www.dolfijntherapievooryara.nl](http://www.dolfijntherapievooryara.nl) (unless you wish to be an anonymous sponsor)

## Dolfijntherapie voor Yara

Om Yara een stap vooruit te helpen

[HOME](#) [PKS](#) [YARA](#) [DOLFIJNTERAPIE](#) [SPONSORS GEZOCHT](#) [NAAMSVERMELDING SPONSORS](#) [DONATIE TELLER](#) [CONTACT](#)



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