



THE OLDEST LITTLE KIDS IN THE WORLD

Bill Sample, 70, is the founder of the children's charity, The Sunshine Foundation. Every year, he holds a reunion for a group of children who are unlikely to live beyond 13 years old, but for a few short days every summer they get to have some real fun

The children mucked about in the heat, strumming inflatable guitars, and for a second it was easy to forget that they were different.

Then Devin, 8, ripped off his T-shirt and I saw his wizened body. Karlita's skin was wrinkled, too, even though she's only 8. And under 7-year-old Maria's bright pink sunhat, she was completely bald.

These children haven't reached double figures yet, but their bodies have been ravaged by old age.

Their joints are so swollen with arthritis they can barely walk and their arteries are hardening.

But to look at them you wouldn't guess they had a death sentence hanging over their heads.

Devin looked up and spotted me. 'When I get big I'm going to be in a band!' he shouted.

I swear I felt my heart break.

Devin, like 40 other kids around the world, has Hutchinson-Gilford Progeria Syndrome. It ages the body eight times faster than normal.

The children are trapped in elderly bodies, and can fall prey to all the problems an old person can. Brittle bones, heart disease, arthritis, strokes, you name it.

Thirty years ago I was working as a police officer, running a charity called The Sunshine Foundation, which grants sick kids' wishes.

One day I read I about a 6-year-old boy called Fransie, from South Africa, who had Progeria.

I contacted Fransie's parents and together we made a plan to fly him to Disneyland.

When a news story appeared about our plans, we had calls from three other families whose children also had the syndrome.

'Please can we come and meet Fransie, too?' they all asked.

'Of course,' I replied.

We booked Fransie and his family into a hotel. It was there we met up with Meg, Mickey and Alicia.

At first the four of them just stared at each other.

'Soon the halls were filled with excited chatter'

But soon the halls were filled with excited chatter as they compared knobbly limbs and bald heads.

This little get-together gave me a brilliant idea.

What if we held a Progeria Reunion? Then all the kids would know they're not alone.

So the following year we invited eight children to Philadelphia for the first Progeria Reunion.

'This week is your week,' I told them.

'There are clowns, bikes, games, toys and musical instruments. You can make as much

noise as you like and eat as many hot dogs as you like.'

'Are we really allowed hot dogs?' one little boy piped up.

Because of the risk of heart disease, they're usually on low-cholesterol diets. But during the reunion, everyone threw the rules out of the window.

'It's hot dogs galore for the rest of the week,' I smiled.

All the kids cheered and

the fun didn't stop for seven days.

The parents benefited too, giving each other support and advice.

It was such a success that as soon as the reunion was over, we started preparing for the next.

The same year, I met my wife, Kate, 49. Thank God, she shared my passion for helping these kids.

When she gave birth to our daughter, Ellen, I was so grateful for our healthy child.

The following year, 30 families from around the world attended the reunion. We all had a great time.

I love each and every one of the kids. When one dies, it's like a member of my family is gone.

I used to go to the funerals, but I've had to stop. The grief is just too overwhelming.

This year we celebrated our 24th Progeria Reunion. Every single child has touched my heart. I won't forget a single one of them.

TURN THE PAGE TO SEE THE MOMENT THE CHILDREN'S DREAMS COME TRUE

CONTINUED

When you die you'll go stra

MEGANE, 13: lives in Nacqueville, France, with her mum, Zoubida Durel, 48

Most parents look forward to their children's birthdays. But I don't. Every year that goes by brings Megane one step closer to the end of her life.

She's 13 now. That's usually when your children are growing more independent. But as each month passes, Megane relies more on me.

Progeria is literally sucking the youth from her bones. Inside, her body is 91 years old.

As a parent, you don't think you might outlive your child.

When you lose your parents, you're an orphan. What are you if you lose your child? There's no name for it because it just isn't supposed to happen.

I struggled to cope after

the diagnosis. Megane's dad committed suicide when she was 5, unable to bear watching his daughter die.

It would have been easy to give into the grief and fear. But I knew I had to pull myself together.

We're so close. I love taking her shopping, although only small children's clothes fit her.

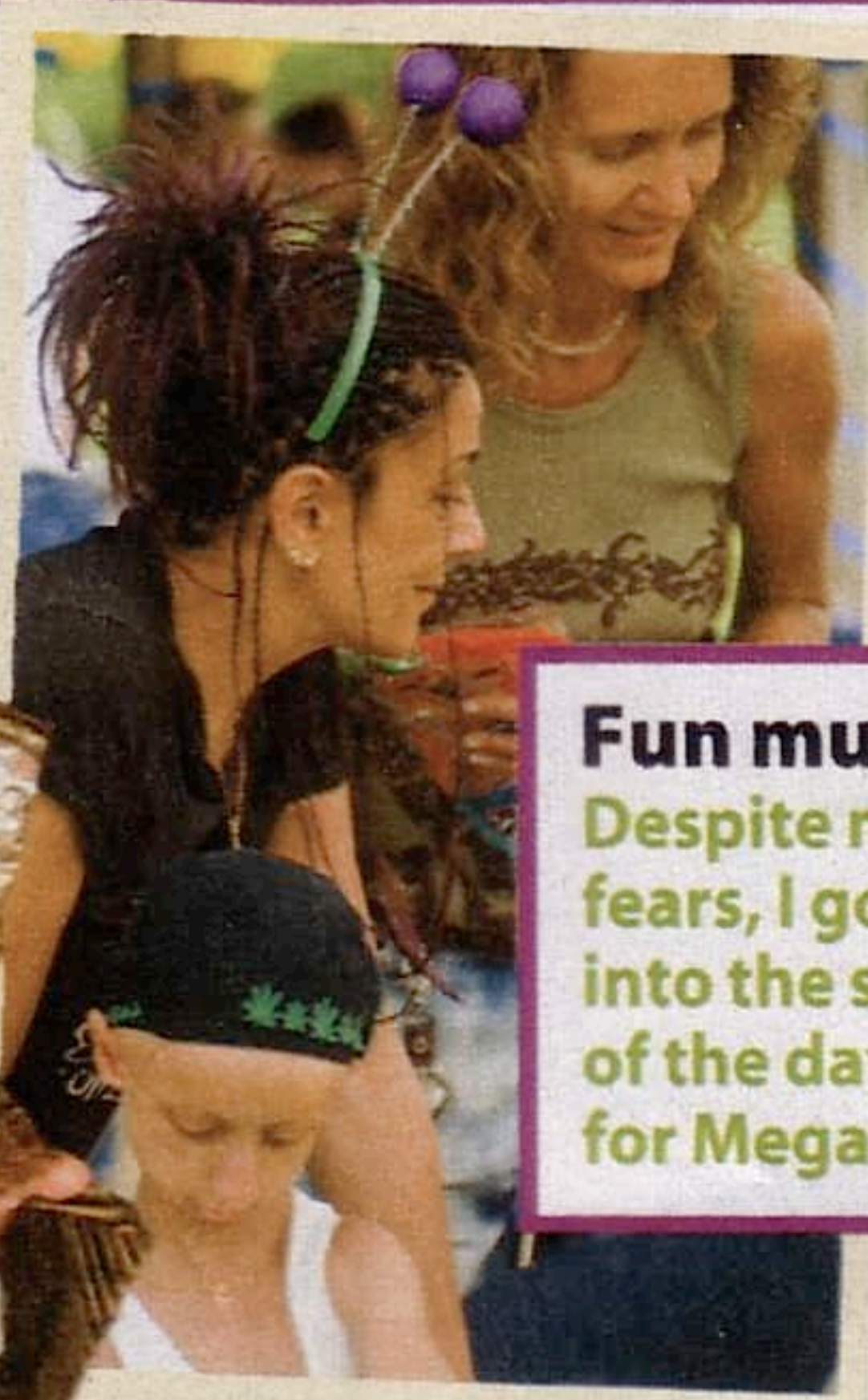
In Philadelphia the other month, we found a trendy, sparkly halterneck top.

'I never find pretty clothes that fit me,' she said, thrilled. 'Thank you.'

I gave her a big hug. 'I'm going



Snappy dresser
Megane at the zoo in her new sparkly top and a snake skin!



Fun mum
Despite my fears, I got into the spirit of the day for Megane

to wear it to the reunion,' she said.

But she looked tired.

'Perhaps we shouldn't go,' I said.

'As long as I can go, I will go,' she replied. 'Besides, this might be my last year.'

Her courage astounds me. She teaches me how to be brave. I feel so lucky to have her.

Megane says:
'I have a short life, so I have to make the most of every moment.'



Take to heart
Megane proudly showed off her 'tattoo' for the rest of the day



Hoopla happy
Michiel's just as boisterous as other 8-year-olds

HAYLEY, 8: lives in Northampton with her mum, Kerry Okines, 32, and family

We've no sooner got back from one reunion than Hayley's talking about the next. It's better than Christmas as far as she's concerned.

But this year was different. Two of Hayley's best friends, Stuart, 18, from Australia, and Sacha, 9, from France, died just before the reunion took place.

Everyone was distraught.

Hayley was diagnosed with Progeria at 20 months old. When the doctors told me she'd probably only live until she was 13, I collapsed on the floor.

My husband, Mark, and I found The Sunshine Foundation on the internet. They invited us to the reunion as soon as we got in touch.

The night before we flew out to America I was sick with nerves. Apart from being small for her age, Hayley still looked like a healthy little girl.

I was afraid to see what she might look like in a few short years.

'I can't go,' I told Mark, as he put the last few things into our suitcase. 'We have to. For Hayley,' he said.

He was right, but even so



Hula girl
She refuses to let her condition stop her having fun

it was agony to see the children when we got there. Their faces were gaunt and their bodies so frail. It broke my heart to think Hayley would look like that one day too.

But the other families gave me a lot of advice and support, and Hayley had a wonderful time.

Now I draw strength from Hayley. She's made me see that even a short life is a life worth living.

Her brother, Louis, 4, adores his big sister and knows he has to play gently with her. My other daughter, Ruby, 1, always lights up when she sees Hayley.

Still, it's hard sometimes, seeing her with mates her own age who don't have the condition. I can't help looking at them and thinking, why my little girl?

Hayley accepts her condition, but sometimes she says the most heartbreaking things.

'Will my hair grow back when my Progeria goes away?' she asked once.

'It's not going to go away,



Face the future
I treasure every precious moment with my little girl

love,' I replied. 'It's going to make you grow older quicker than your friends.'

I won't lie to her, but she doesn't need to know everything about the disease just yet. She may have the body of an old woman, but I want her to keep the mind of a child.

Hayley says: 'When I go to heaven I want to have blonde hair, like Kylie Minogue.'

ight to MY HEART

MICHEL, 8: lives in Belgium with his dad, Wim Vandeweert, 39, mum Godelieve, 36, and sister, Amber, 6 months

The spirit is willing but the flesh is weak. We've all heard the saying, but in my son's case it's eerily true.

Michiel's body may be frail and old, but his mind is young and active.

The other day, we went to collect him from school and a few of his schoolmates were having a kickabout with a football.

There was Michiel, right in the middle of the action, skinny legs pumping furiously as he ran up and down the field.

'To me, to me!' he shouted at the lads who were twice the size of him.

I watched, cringing. A fall or a bad tackle could mean a broken leg for Michiel.

'Be careful!' I called to him. 'Oh Dad, I'm fine,' he said, rolling his eyes.

My wife, Godelieve, and I decided we had to let him be a normal little boy for as long as possible. But it's hard not to worry.

Michiel was 5 when he was diagnosed

with Progeria. He'd been sent to see a specialist when he was 6 months old because he wasn't growing properly.

Finally, we were told to watch a programme about a young girl with Progeria.

'That's what Michiel has,' Godelieve sobbed when we switched it on.

Tests confirmed the diagnosis. If he was lucky, he had 10 years left to live.

We were both devastated, but Godelieve found it

particularly hard.

'We have to stay strong,' I told her. 'We can't let him see that we're scared.'

Later that year we attended the Progeria Reunion. It was hard to see the older kids with their gaunt faces and limbs gnarled by arthritis.

My best mate
I'm going to make the most of the time I have with my son

Above par
Watch out Tiger Woods! Michiel's a star at golf

It was like looking into the future.

Michiel made friends easily even though he didn't speak

a word of English.

'How do you talk to them?' I asked him.

'I just wave my arms around,' he replied.

Michiel knows he has Progeria. He doesn't know he'll die young. I don't think he needs to know about that yet.

His optimism amazes and humbles me.

'I want to ride a motorbike when I get big,' he told me last month.

'I'm sorry, Michiel,' I replied. 'You're always going to be too small.'

'I WILL grow,' he told me.

We still have days when we're crushed by sadness. But Michiel's happy and positive outlook gives us the strength to face each day with a smile.

Michiel says: 'I love everything about the reunions, but especially the hot dogs.'

DEVIN, 8: lives in Ontario, Canada, with his mum, Jamie Scullion, 32

As soon as Devin was born I knew something was wrong. He had huge, round, blue eyes, almost too big for his head. His skin was paper thin and I could see the blue veins running underneath.

Devin was my first child, but I'd been around enough babies to know he was different.

'Your baby's fine,' my doctor said. Still, I couldn't shake the nagging

worry that something wasn't right. I was raising Devin alone and had no one to share my worries with.

When Devin was 4 months old I took him to a paediatrician.

'Your son has a genetic disease called Progeria,' she told me.

'The ageing disease?' I gasped.

I'd seen a child with Progeria on a talk show.

The paediatrician had recognised the signs the moment she saw Devin. The lack of pudgy baby fat and the thin, papery skin.

I was beside myself. My tiny little boy had only just been born, and he was already dying.

I'm going to give him the best life I possibly can, I vowed.

Even though I was terrified, as he grew up I never let

him see me get upset. I wanted his short life to be filled with happiness.

He rides his bike and plays

with his train set. It's hard not to be overprotective, but I have to let him be a 10-year-old boy.

I've always been totally honest about his disease, and the fact he would die.

A couple of months ago, he came up to me.

'Mum,' he asked. 'What's it going to be like in heaven?'

'You're not going to heaven,' I replied.

'What do you mean?' he asked, his eyes wide.

'When you die you're going into my heart,' I said.

'And you're going straight into my heart,' he said.

Until then, we'll both carry on looking forward to the Progeria Reunion. For one week each year Devin isn't different. He's the same as the other kids.

Devin says: 'I like the reunion because everyone is like me. We all look the same.'

By Jacqui Patterson
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Having a ball
My boy loves the reunions

Rock 'n' roll
Devin's so good at the guitar he needs two!

ERIA REUNION
23-28. 2006
DELPHIA, PA