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Lifestyle SA Weekend

The Amazing Enzo: South Australia's one-in-20-million kid

Enzo Cornejo is Australia's one-in-20 million kid, a boy who loves playing with his friends but is also rapidly ageing. It's not slowing him down, though.

Penelope Debelles

15 min read September 23, 2022 - 12:00PM SA Weekend

 20 comments

Enzo Cornejo, 11, is the only known Australian with progeria, the disease of premature and rapid ageing. Just don't expect it to slow him down or dampen his...

SA Weekend

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Meet Enzo Cornejo, Adelaide's one-in-20 million boy who is squeezing more joy, friendship and Vegemite into a day than most of us.

Diagnosed with the rare condition progeria – the disease of premature and rapid ageing – this bright and energetic 11-year-old is shrugging off medical complaints usually associated with the elderly, such as high blood pressure and cholesterol, and the risk of arteriosclerosis.

The only known Australian with progeria, Enzo hits the ground running each day, just another boy at school who loves playing with his friends.

“I like being different because I love my body,” Enzo says. “Also, I’m a handsome boy. I’m happy just being me.”

Enzo, who is in year 5 at St Mary's Memorial School, Glenelg, has reached an age where his parents, Catherina Llontop and Percy Cornejo, want him to be a more familiar face in the Adelaide community, so he can move around without a fuss. He is well known at his school where new students are told there is a special boy ahead of them. But he has not been introduced more widely before because he was too young to talk about it.

He grew up knowing he was special but only understood progeria about a year ago after Llontop and one of his therapists compiled a My Story booklet that charted his birth, diagnosis and symptoms. It gave him the language he needed to talk about it.

“It kind of makes my body very old, very quickly,” he explains. “It makes my veins very visible and also my heart is very delicate, and I don't have much hair.”



Enzo Cornejo with his iPad, where he uploads content for his YouTube channel, Enzocubehead. Picture: Matt Turner

He doesn't mind when people come up and ask questions about why he looks the way he does and says talking about it does not make him sad.

"It's okay for them to come up and ask questions in a respectful way," he says. "Like, 'Enzo, hello, how come you don't have much hair?' Or 'Why are you smaller than me?' So long as they say it in, like, a positive way."

He is proud of being special and knows there is no one else in Australia like him. "There was another one in Victoria but he sadly died," he says. Their families are close and support each other, and Enzo wishes he could have met the boy, Chris, who died just before his 21st birthday in 2003, before Enzo was born.

Much of his day is spent on his iPad where he makes videos for his YouTube channel, Enzocubehead, while fitting in full-time school and a range of specialist and therapy appointments, and seven daily medications.



Enzo's YouTube site features many creative movies, often featuring his favourite food: Vegemite.

He manages all this with the support of a network of doctors, therapists, teachers and his parents who did not know until Enzo was three that there was something wrong, and that Enzo would face challenges only a few hundred others around the world could understand.

Llontop and Cornejo are Peruvian immigrants who came here in 2007 seeking a better future for their family.

Enzo was their first, very wanted child and he was born eight weeks premature on August 31, 2011.

His skin texture was different, not quite baby soft, but his premature birth could have accounted for that.

“We weren’t worried. He was happy and he was in the 95-percentile range at that time,” says Llontop who works as a financial accountant in the city but prefers to be known as Enzo’s proud Mum.

His growth later dropped below average but he was a chubby-cheeked toddler with big brown eyes and there was nothing obviously wrong.

There were certain baby things he couldn’t do and some motor delays but he was free of pain, and happy.

Only when his growth dropped well out of the range for his age did his paediatrician start looking for an underlying cause.

ENZO’S DIAGNOSIS

Just before he turned three, his genetics doctor ran detailed tests that eliminated one possible condition, which left the test for progeria.

Llontop had come across progeria once before but knew very little about it. “The name stuck in my mind,” she says.

When the results came in, the doctor called and asked if her husband was coming too.

She didn’t realise then but it was a sign of what they were about to hear, a diagnosis so rare that none of his doctors in Adelaide had ever encountered it.

Enzo came to the appointment too and Llontop thinks it made them stronger to hear the diagnosis with him in the room.

“We went and he told us and said he knew of a progeria group in America who were doing trials,” Llontop says.





Enzo loves the Adelaide Crows and talking all things footy. Picture: Matt Turner

They were given information about the Progeria Research Foundation (PRF) in the US which is the only organisation running clinical trials or searching for a progeria cure. The foundation's work, more than anything, has given them hope.

They were provided with a list of South Australian doctors Enzo would start seeing and who would become part of a network of sustained medical and community support.

“At that moment we didn't know how different life was going to be; a new world was opened,” Llontop says. “What we did was make a list of all the things we needed to do.”

Llontop and Cornejo, a chef, took time off work to research the condition, learning as they went along. They contacted the PRF in America that week, began paperwork for the NDIS, talked to his childcare about extra help Enzo might need, and booked in to see his new doctors.

“We knew we had to be very careful with him,” says Llontop, who found support from other families overseas through the PRF and a private Facebook group. One of the first American mothers to contact her was the mother of Zach who Enzo met later at a progeria camp.

The following April the family flew to the US and Enzo has now been through three clinical trials. As a result of one of them, the medication Lonafarnib was approved as a treatment for progeria and is now prescribed and delivered to him through the Women's and Children's Hospital.

MANAGING THE CONDITION

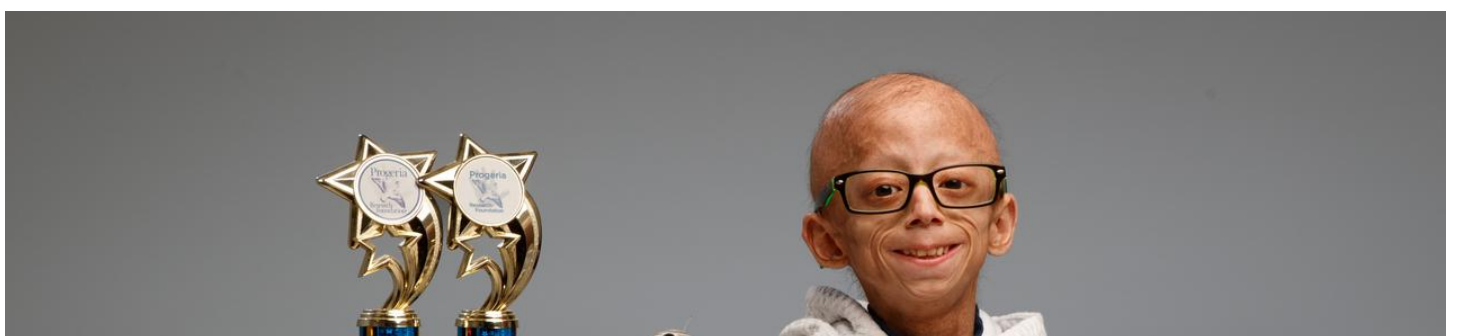
At 11, he is tiny and frail and care must be taken to create safe spaces so he is not accidentally knocked over, although Llontop says that now he is older he knows how to look after himself and safely hang out with his friends.

He has grown especially close to his paediatric physiotherapist Tanja Samira Jorgic Rudd, who is involved with his care and has worked with the family since he was young.

Rudd, who is in Switzerland with her family and grew up in Brazil, chats with Enzo and the family regularly, and says the focus is on maintaining his mobility and strength rather than trying to regain it.

“It is a gradual, degenerative condition so we treat individual goals rather than the condition itself,” she says.

One of the reasons he is living his absolute best life is a small school at Glenelg which could not have been more welcoming and inclusive.





them know he was tiny, and would remain so, and that there would be other changes to his body as he got older.

“Initially, he was probably the same size as the reception students so there wasn’t a lot that needed to be done,” Izzo says. “Since then, we have made some mild modifications to toilet seats and so on.”

The children took Enzo under their wing and embraced him from the start. He is friends with everyone, full of beans and talks almost non-stop.

“Some of my staff acknowledge him as the Energiser Bunny, he won’t be quiet!” Izzo laughs. “Any topic that you raise, he will start talking about, he is full of life basically.”

The whole of the school knows they need to be gentle around him, that he can’t fall over, that his skin is thinner, his bones are fragile and he gets out of breath.

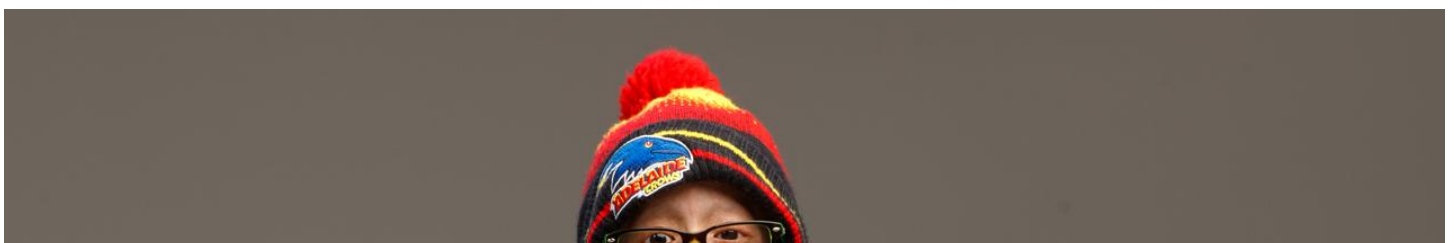
On the school’s Friday walk to the beach, a wheelchair is on hand so Enzo can jump out on the way if they stop, and play when he gets there. Without that, he would be too tired to join in.

Rudd, who does hydrotherapy with Enzo, also visits him at the school and spends time with him playing one-on-one basketball or soccer, sports that would be too dangerous for him in a rough-and-tumble setting.

“For lunch and recess, he often stays in the library or uses a small corner of the yard,” Rudd says. “Quite often (physio) is about allowing him to experience activities and movement he is not always able to do with his peers.”

The school also supports him in other ways, with teachers shaving their heads or cutting their hair to raise funds for Team Enzo and the registered Enzo Cornejo Necessitous Circumstances Fund that covers the family’s trips to the US.

“Each year we have an Enzo day – ‘hats on for progeria’ – and we all buy a hat and support his cause,” Izzo says. “A couple of teachers who were with him at the beginning have become virtually a part of his family.”





Has he ever been bullied at all:

“No! Not for 11 years,” Enzo says. “Because my friends are nice to me, I have made so many friends, everybody is my friend.”

Sometimes, a story will come on the news about bullying and Llontop says Enzo is sad for them and says, “that kid, they should go to my school”.

“I feel sorry for kids who get bullied,” Enzo says. “Also, I think I feel sad for the bullies as well because I think they were bullied by others. And then they don’t have a happy life.”

A lot goes on behind the scenes to make sure he doesn’t miss out on having fun. He has just transitioned from a manual scooter to an electric one so he can keep up with his friends without tiring. He is also practising using his new wheelchair which is the manual one he has had for five years converted with a small machine to a much cooler electric-powered version operated with a wristband app. He doesn’t have it at school yet but may try it out later this year.

“Now he loves his wheelchair, now he’s basically got a little car, he’s faster than his friends and everyone is jealous of him,” Rudd says.

His medical team read up on the condition but none of them had handled a progeria diagnosis. “We don’t know about progeria, so maybe you know more than us!” the doctors basically told the family. His primary care is through a metabolic clinic team, who control the medicine for progeria, and he also regularly sees other specialists including a cardiologist, a neurologist and renal clinician. His blood pressure went up last year so he had a short time in hospital while it was brought under control and is back to normal.

“Everything is stable and positive,” Llontop says.

The school says he has taken on challenges as they emerged and adapted brilliantly along the way.

“His parents have told him more and more and as he got older, he has accepted it. Now he will say to you ‘I love my body the way it is’,” Izzo says. “He has come a long way. I think having others around him who say ‘it doesn’t matter what you look like, it doesn’t matter if you have hair’, or whatever, has helped to build his self-esteem.”



Enzo is a very fussy eater. At Montezuma's restaurant at Glenelg, where Cornejo is the cook, he has in front of him a snack box whose key ingredient is his favourite food, Vegemite. He is eating it straight off a tiny spoon from a catering pack his mother gives him to ration how much he consumes. Left to himself he would eat Vegemite from the pot and would get through a pot in a day. He should be sponsored by Vegemite, Llontop laughs.

It's all about the salt, she says, which also explains his love for KFC chips, his second favourite food. Other than that, he struggles to eat and doesn't have a sweet tooth or look forward to mealtimes.

"He is getting better but for a time, all the medications had to be given in liquid form," Llontop says. "Now, this year, he has started to swallow and he can take the pills. He is very food negative but with medications he is really good. He tells me if I am late."





A while ago Llontop was told about an audition for Embrace Kids, the body-positive documentary being made by Adelaide's Body Image Movement founder, Taryn Brumfitt and [featured in SA Weekend last month](#). They were looking for children in Enzo's age range who were interested in body image and diversity and who had a story to tell. He applied, was accepted, and made more friends.

Llontop says he was confident and proud and the documentary was a milestone for him because for the first time on camera he says, "I have progeria". He was one of 18 children who spent close to three days at a workshop at Port Adelaide talking about body image, self-esteem and bullying. Llontop had never left him alone in a strange place before but by the second day, he was so at home and well cared for by the Embrace Kids team she was happy to go.

Enzo says he auditioned because he thought he would like it and have some fun.

"It was good to meet other kids and talk about their bodies and other things," he says. "Taryn asked us questions about what we don't like and I made friends over there."

He mentions one young girl who had been bullied, and he still feels bad about that.

"She used to get really sad because people laughed at her, and I feel sad for her," he says. Far from being intimidated by the cameras and lights, Enzo smiles his way through a piece on camera, pronouncing himself happy and handsome.

His secret dream, like many kids his age, is to be a YouTuber with lots of followers. While we are chatting, he picks up his iPad and checks because he thinks he might have picked up a subscriber. His self-made videos, which he is happy to talk about at length, feature a common theme around a Vegemite superhero conferring superpowers and wielding Vegemite breath to save the day.

"He wants to become the next influencer," principal Nat Izzo says. "He loves technology and has his own YouTube channel and he sees himself as an influencer. He has a group of children who follow him closely and support him."





There was no rule book to follow when raising a child with progeria but his parents have always told him what he needs to know. “We never lie to him; if he has a question, we tell him what the answer is,” Llontop says.

He is a happy and well-adjusted child who is the focus of a small and very supportive Team Enzo community, which has come to include his broader medical team.

“I think that all the people who are involved with him are on the same page,” Llontop says. “I think it is fate that the people who came to us are the right people.”

His next big step will be high school and, after a lot of research, he will in 2024 move to Sacred Heart, a Marist Catholic school where most of his St Mary’s friends are going. Ahead of starting a new school, his family wants to introduce him more widely to the community to make the transition to high school easier, which Enzo understands and supports.

“So, when I get there, they know me and say ‘there’s Enzo!’,” he says.

The transition to an electric wheelchair is part of preparing for Sacred Heart which has a much larger campus for him to cover. He is learning how to manoeuvre it, to dodge obstacles and safely navigate through a busy street or playground.

“He lives 100 per cent for the moment but using powered movement was part of us planning ahead,” says Rudd, who will be back from Switzerland soon after Enzo starts high school. “Possibly in a year or two’s time he may be relying completely on his wheelchair so we need to make him completely comfortable and skilled.”

He likes being special and enjoys the status that being Australia’s only known progeria kid brings. Llontop says Enzo is not scared of the limelight and is basking in a bit of glory after his involvement with Embrace Kids was featured on Channel 10’s The Project.

“Yes, I like it. One of my little kid friends said to me ‘I heard that you were on The Project, you’re famous!’,” Enzo says. “That’s why I’m getting more confidence. There is no other kid like me in Australia.”

He also stars in a new video linked to the Team Enzo website which was made at St Mary’s Memorial School. He is introduced by Izzo who hands over to Enzo to tell his story.

“I love being popular,” he says, before explaining he is trying to learn to eat vegetables because he knows they are good for him. He is just as smart as others his age even though he is smaller, he says, and while progeria is part of his life, it is not all of it.

“Progeria does not define me,” he says on the video. “But I must do some things differently to continue enjoying my life.”

Rudd says his parents have done an exceptional job in raising a happy, positive child and reminding him to smile at the world every day. “The reality is, I think he just feels so loved, it is incredible,” Rudd says.

Enzo says he is happy just being himself. “Because I like to be veiny, I like to be skinny, I don’t want to change,” he says.





A FILM BY TARYN BRUMFITT, CREATOR OF EMBRACE

LOVE
IS
A
BODY

JUDGE
LESS
LOVE
MORE

Embrace Kids

move
nourish
respect
enjoy

I AM
ENOUGH

be
real

YOUR BODY
IS NOT AN
ORNAMENT



ERIN
PHILLIPS

CELESTE
BARBER

FEATURING
JAMEELA
JAMIL

AMY
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ELECTRIC
FIELDS

THE FIRST STEP IN CHANGING THE WORLD IS CHANGING YOUR MIND

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Enzo features in the movie Embrace Kids.

He can still do the things he likes, such as dancing and playing on bouncy castles, but jumping can be hard on his hips and body so it is more of a special occasion than something he does every day.

On the St Mary's Memorial video, his school friends describe him as funny, kind and always smiling, a good friend to have around and to play robots with, or online games. The staff say they find daily inspiration in their small student whose philosophy is to be happy, smile and enjoy life.

“He thinks he is as popular as Lady Di,” Llontop laughs. “It doesn't bother him to be known and to be popular because when people already know him, they can just say to him ‘hello Enzo’. Just that. ‘Hello’.”

There will be a screening of Embrace Kids at Mitcham cinemas on Sunday, September 25 at 11am to raise funds for Enzo. For details go to teamenzoprogeria.com

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The world would be a much better place if we were all half the quality of human that Enzo is.

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