

Howick and Pakuranga Times
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Our Homes TODAY



Front Page Feature

Bleeding disorder keeps boy busy

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CONFIDENT BATTLER: Andrew Scott, pictured with his mum Lynley, independently manages his haemophilia A with injections three times a week. Times photo Jackie Russell.

WHEN a bright-eyed boy is mad about Lego, swimming, bike riding and PlayStation, it's easy to overlook the serious condition he casually deals with every day.

Andrew Scott is a vibrant nine-year-old who lives an active life with haemophilia A.

Misconceptions that he will bleed profusely from the smallest nick can make those around him fear for his safety, but he won't bleed faster – he will just bleed for longer.

His mum Lynley Scott says Andrew bruised often and badly when he was a toddler finding his feet. Many people commented about this, which was challenging for the family.

Now, small internal bleeds in his knees are most likely to cause him pain. "The joints fill up with blood and become painful," explains Lynley. "Because Andrew has had so many, he picks them up quite quickly.

"He doesn't tend to have any outside physical symptoms – he'll say to us, 'my knee feels funny, I must have a bleed'."

Keeping active is important for Andrew and he's joining in the soccer fun day at his school, Elim Christian College, but contact sports such as rugby are out of bounds.

"My friends know I have haemophilia and I'm the only person in school who has it," says Andrew.

"They know they need to be careful with me."

He doesn't worry about being injured when playing with his friends. He knows his limitations, and his parents are now confident he can handle situations.

"Someone said to us if he doesn't have bleeds then we know you've wrapped him up in cotton wool," says Lynley, of Pakuranga.

"He's a boy and has to do things, but must take precautions as well."

Each year his new teacher learns about Andrew's haemophilia and the school is confident about handling his condition.

"I know what to do – I just need to know that they trust me," says the youngster.

"I would like it if people let me be who I am, and let me do what I want to do and just watch out for me if I'm in trouble – but not interfere."

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When he was younger, Andrew had numerous hospital stays.

Now he injects an essential blood-clotting substance, which is called factor VIII, into his blood stream three times a week.

Andrew's deficiency of factor VIII is an inherited condition but he's the only one in his family with haemophilia A.

He started giving himself the injections consistently at the beginning of this year.

"The reality is these kids have to have it [medication], and our aim was to make Andrew as independent as possible," Lynley says.

Injuries to his head or around his airways can be critical, but he can cope with most other situations.

Families with children who have severe haemophilia learn to give prophylactic treatment at home, whereas children with less severe conditions have on-demand treatment.

"It does affect him but we don't want it to be the sole thing about Andrew," says Lynley.

Action-packed school holidays included a Haemophilia Foundation new families' camp at Rotorua for the Scott family.

They joined other families who have haemophiliac under-10s, including some from East Manukau with children who have another form of haemophilia, Von Willebrands.

As Andrews grows, the foundation offers more camps and support networks. "It's great to see the kids all active together and not feel like they are alone in this," says Lynley.

Families learn from each other and gain strength, and Lynley and her husband Richard find it rewarding to support new families.

In July, they are off to the biennial congress of the World Federation of Hemophilia in Argentina.

"The treatment of haemophilia has changed so much in the past 20 years and now our kids are not disabled," Lynley says. "Years ago when they didn't have good regular treatment, they ended up in wheelchairs and on crutches with bad arthritis."

Previous generations also battled HIV and hepatitis C from infected blood products, whereas today's children receive synthetic treatments.

"We've learnt pretty quickly that Andrew's not going to break."

HAEMOPHILIA DAY

THE theme for World Haemophilia Day on April 17 is "the many faces of bleeding disorders."

- In people with bleeding disorders, the blood cells called platelets do not work correctly or are in short supply.
- They bleed for longer than others, but medicine enables them to live full and active lives.
- The most common type of haemophilia is factor VIII deficiency, known as haemophilia A.
- The second most common type is factor IX deficiency or haemophilia B, which is sometimes known as Christmas disease.
- Both haemophilia A and B are very rare disorders. Estimates indicate that approximately one-in- 10,000 males born in New Zealand have haemophilia.
- Recent studies suggest that about 300 New Zealand residents have haemophilia.
- For more information, log onto www.haemophilia.org.nz