



ST JUDE'S PRIMARY SCHOOL

Mulley Street, Holder ACT 2611
PH: (02) 6288 7688 FAX (02) 6288 7101
EMAIL: office.stjudes@cg.catholic.edu.au
WEB: www.stjudesps.act.edu.au

Dear St Jude's Primary School Families

Our children Oliver and William will commence at St Jude's in 2017 and with the support of the school we'd like to tell you a little about William's diagnosis. Over the years, we have found that sharing some information about Will's condition is helpful for both parents and children and in turn helps Will to feel more comfortable as children overcome their initial curiosity and then see Will for who he is.

Will is six years old and will be starting in Year 1 and he has a condition called Achondroplasia which is the most common form of dwarfism. Below is some information you may find useful:

- 80% of people with Achondroplasia are born to *average height* parents, as is the case in our family;
- There are more than 300 types of dwarfism, with Achondroplasia being the most common;
- The condition affects bone growth resulting in shorter stature, and disproportion head size and limbs;
- People first language is an essential element of an inclusive environment so if we need to describe Will's condition to someone we explain that 'Will has Achondroplasia' or 'Will is short statured';
- In our family, we refrain from using the word 'dwarf' and the word 'midget' is viewed as extremely offensive;
- You may find it helpful to explain to young children that Will has special bones, in fact this is a term that Will still uses when children ask why he is so small; and
- Will's condition does not affect his cognitive or intellectual abilities and he is very determined to give everything a try, even if it's in a slightly different way.

Will has had numerous surgeries over the last six years, the most critical was his spinal decompression surgery - for this reason it is very important that Will is not picked up or engages in rough play as he more susceptible to spinal cord injury.

A message from Will:

Hi, I'm looking forward to making friends next year. I like monster trucks and tek deks, playing soccer, art and music, and at my old school I had fun learning Italian. Please remember that I'm not a baby – I'm just small that's all. I don't like to be patted on the head or picked up, but if you see I can't reach something you can offer some help. I'm really excited about my new school!

Thanks for taking the time to read our letter. If you have any questions or are not sure how to answer your child's questions, please don't hesitate to contact us rowena.muir01@gmail.com or speak with your child's teacher. Alternatively, the Short Statured People of Australia (SSPA) has some really great information www.sspa.org.au

Kind regards

Rowena, Matt, Ollie and Will Muir
13 December 2016