

How to host your 'Sprinkles for Sanfilippo' morning tea

Thursday 16 November is World Sanfilippo Awareness Day and we invite you to help spread awareness and support the work of the Sanfilippo Children's Foundation by hosting a 'Sprinkles for Sanfilippo' morning tea!

Hosting a morning tea is a great opportunity to get together with friends, family or work colleagues, at your day care, school or community centre and enjoy a chat, a cup of tea and a sweet treat. Not only will you help more people learn about Sanfilippo syndrome, you can also support our vital work to drive research and find a cure for this devastating condition.

Step 1: Get your morning tea organised

Pick the time and place for your morning tea and decide how you're going to cater it. You may want to be chief baker, outsource this to a local supplier, or plan to get a bunch of people to contribute goodies! If you're doing this at your workplace, see if your employer will support it by providing morning tea, or even match any donations from staff. If you're getting your school or day care involved, see if they can help by asking parents to provide baked goods, or if your P&C Association or school leaders want to be involved.

Step 2: Spread the word

Tell your colleagues, friends, school community, family etc that you are hosting a Sprinkles for Sanfilippo morning tea and invite them to come along. If you have a Facebook account, you can set up an event or spread the word online. You can also download printable posters from our website to help promote your morning tea.

Step 3: Many hands make light work!

Encourage your colleagues, parents in your school community or friends to bake cupcakes, cakes, muffins, slices - anything they like! - and use purple icing and/or sprinkles to decorate these in honour of children with Sanfilippo syndrome.

Step 4: Ask guests to make a small donation for their morning tea

There's lots of ways you could do this, including:

- Asking people to contribute a gold coin for morning tea
- Providing a QR code and the website URL so people can make an online donation
- Setting up a fundraising page on the Sanfilippo website and asking people to donate through this (this is a good option if you are organising morning tea for a large company or organisation, or if you want to get your community behind the cause).
- Funds can be directly deposited to our account (donations over \$2 are tax deductible). Bank details are Sanfilippo Children's Foundation (BSB - 082 057, Account - 392042188).

After the event, don't forget to share your photos on your social media page and tag us, as we love to see everyone's hard work and beautiful cakes. Thank you for helping to shine a light on this devastating condition.

Help to raise awareness - get to know the Facts about Sanfilippo syndrome

- Sanfilippo is a rare genetic condition that causes fatal brain damage. It is a type of childhood dementia and most children never reach adulthood.
- Sanfilippo is considered a rare disease: 1 in 70,000 children are born with the inherited condition. However 1 in 169 healthy adults carry the faulty gene that causes Sanfilippo.
- Sanfilippo mostly affects the brain and is one of a group of conditions called 'childhood dementia'. Over time, brain cells fill up with waste that the body is unable to process. As the brain gets progressively damaged, children experience severe hyperactivity, disordered sleep, loss of speech, cognitive decline, cardiac issues, seizures, loss of mobility, and finally death, usually before adulthood.
- There is currently no treatment or cure available to children diagnosed with this devastating disease. However there is promising research and clinical trials in train, providing hope a cure will soon be found with continued investment in medical research.
- To find out more about Sanfilippo syndrome and the Sanfilippo Children's Foundation you can visit our website – sanfilippo.org.au.

Useful links:

www.sanfilippo.org.au

https://www.youtube.com/watch?v=6-HA_A3tPqQ