

SUNDAY MASS	
Saturday Vigil	6.00 pm
Sunday	9 am, 11 am
WEEKDAY MASS	
Monday (Springvale)	9.30am
Tuesday	9 am
Wednesday	9 am
Thursday	9 am
Friday	9 am
Saturday	9 am

The **Sacrament of Reconciliation** is available 30 minutes before each weekday Mass, after Saturday morning Mass and by appointment.

THERE WILL BE NO CONFESSIONS ON ALL FRIDAYS OF LENT

HOLY ROSARY
 Tuesday—Friday 8.35am
 St Joseph's Church

Wednesday 1pm
 St Joseph's Parish Centre
*15 Decade-Rosary
 Mary Untier of Knots*

FRIDAY DURING LENT
 8.30 am Stations of the Cross followed by Mass at 9.00am

PARISH OF ST JOSEPH CHELSEA

3rd Sunday of Lent 12 March 2023

A RARE DISEASE JOURNEY—NIAMH AND MAREE DALTON—Part 3

Weeks of Lent Themes – Week 3 – God speaks, God is with us, God calls us

Niamh loves going to school. She would rather interact with people than watch TV or look at a book. The Physiotherapists at Nepean school used to race to be the one to work with Niamh, because she never grumbled and tried hard to do all the work set out for her, and always with a smile on her face. Niamh participated in a number of school concerts at Nepean, wearing beautiful costumes and delighting the audience with her big smiles and interactions with others.



Meanwhile, medically we were still searching for answers in regards to what was causing Niamh to continue to have seizures, struggle with her motor skills and lose her abilities. Niamh was also referred to an Ophthalmologist, an eye doctor specialising in complex issues. No vision issues were detected, however a cherry red spot was found on her macula, an indication of a metabolic disorder of some type.

In January 2017, Niamh's Neurologist Professor Ingrid Scheffer advised that new testing for unknown epileptic diseases was occurring on a trial basis. She asked if we could conduct this with Niamh, which I whole heartedly agreed to, as the search for answers was in its 7th year. This testing was called whole exome sequencing and looks at all 26000 sets of chromosomes in order to identify which are not behaving as they should. Rather than just look at one potential disorder, sequencing looks at the whole genetic makeup of a person.



As Niamh attends a government school due to her disabilities, I organised for her to complete her first Reconciliation through our Parish OLHC in Narre Warren, and she fulfilled this, with her cousin Sebastian on the 22nd of April 2017. Father Brendan Hogan sat and quietly talked to and prayed with Niamh, as she was now non-verbal. It was a beautiful celebration and Father Hogan was wonderful in his dealings with Niamh.



It was with trepidation that I attended the Austin Hospital for Niamh's results from whole exome sequencing on the 27th of July 2017. After 8 years, a diagnosis, but most definitely not a good one. GM1 Gangliosidosis. The appointment was a blur, horrifying words about regression, short life expectancy and loss of all abilities. Heart-breaking and very hard to deal with.

I commenced researching, finding that GM1 is a very rare disease, with only 3 cases in Australia. Most of what I found was through the Cure GM1 foundation in the USA – founded by the mother of a child with GM1, and the NTSAD, also in America – The National Tay Sachs and Allied Diseases group of which GM1 is an allied disease. I also contacted the National Institutes of Health (NIH) in Bethesda USA as they were conducting studies into GM1.

Continued in middle pages...

PARISH PRIEST
 Rev Kevin Williams

PRESBYTERY & PARISH OFFICE
 362 Station Street Chelsea 3196
 Tel. 9772 2211 Fax: 9776 0025
 Email: chelsea@cam.org.au

PARISH OFFICE HOURS
 Tuesday - Friday 9am—2pm
 Deadline for Bulletin 12 noon Thursday
 Baptism, Weddings, Parish Centre enquiries:
 Parish Office 9772 2211
 Parish Website <http://pol.org.au/chelsea>

SISTERS OF ST PAUL DE CHARTRES
 78 Argyle Avenue, Chelsea Tel 9773 9295

ST JOSEPH'S SCHOOL
 Tel. 8773 1111
 Principal: Gavan O'Donnell
www.sjchelsea.catholic.edu.au

St Joseph's Parish is committed to the Safe-guarding of Children and Young People in all aspects of Parish life.

To subscribe to St Joseph's Parish emailing list please email chelsea@cam.org.au

The solemn obligation for baptised Catholics to attend regular Sunday Mass has been restored throughout the Archdiocese of Melbourne.



Prayers for the Sick
 Danielle Spencer, Malcolm Russell

Anniversaries
 Jack Burns, Jerry Daniels, Timothy John O'Dea, Maude Pereira, Valeriano Azavedo

Birthday Remembrance
 Edna Godlieb

12th March; 3rd Sunday of Lent A
 1st R: Ex 17:3-7
 2nd R: Rom 5:1-2, 5-8
 Gospel: John 4:5-42

19th March; 4th Sunday of Lent A
 1st R: 1 Sam 16:1, 6-7, 10-13
 2nd R: Eph 5:8-14
 Gospel: John 9:1-41



Please do not attend Mass if you are unwell.
 There are no numbers restrictions on attendees at church.
 Face masks are no longer mandatory inside the church, but their use has been strongly encouraged by the Archbishop.
 Please use the hand sanitiser provided.

PARISH CALENDAR

SATURDAY 11 MARCH

4:30pm Our Lady Star of the Sea Junior Legion of Mary—any enquiries or information please contact June Pereira on 0403 095 627
6:00pm Men's Choir at Vigil Mass—practice 4:30pm prior to Mass

MONDAY 13 MARCH

Labour Day Public Holiday

TUESDAY 14 MARCH

10:00am Sacred Heart Prayer Group—Room1
7:30pm KSC Branch Meeting—Nazareth Room

THURSDAY 16 MARCH

10:00am Film and Light Lunch—Please bring a plate—Nazareth Room

FRIDAY 17 MARCH

Feast Day of St Patrick
8:30am Stations of the Cross—Church



Did you know.... About 50 Bibles are sold every minute. It is the world's best-selling book. Some 1 billion copies of Bibles have been sold.



ST JOSEPH'S PARISH STEWARDSHIP

Weekly Pledge \$ 2,737
Weekly average \$ 2,052.50



St Vincent de Paul Society Week 4

Washing powder, dishwashing liquid, household cleaning items. Please leave your donations in the Vinnies bin in the Church narthex. Thank you for your donations.



New volunteers for St Vincent de Paul Chelsea Conference are always welcome. Please contact Carole if you are available to help on 0404 335 419



Longbeach Parishes Social

Next Social - Wednesday 22 March for Dinner at Doyle's Hotel (The Bridge) Mordialloc starting at 6pm. All welcome. For bookings please ring Patricia Adams 0488-866-020 or Keith Reiter. 0417-350-733 or leave a message on 9772-7292.



Readers & Ministers of Holy Communion

Rosters are now being prepared for the next quarter. Contact Chris Bennetts on 0402 823 040 or cjbennetts@optusnet.com.au by **NEXT Sunday 19 March** if you are unavailable during this time



The Missionary Sisters of St Peter Claver will be holding a *Book and Plant Sale on Saturday 18 March 9am-2pm. 154 Cotham Road Kew. Proceeds from the sale will go to assist the many needs of the Missions. Enq: 9817 3715*



The Word Among Us Easter 2023 Edition

Subscribers to the magazine can collect their current issue from the Church



Zimbabwe is experiencing an intense drought, exacerbated by climate change. With the support of Caritas Hwange, Priscilla learnt conservation farming skills to grow drought-resistant crops and started poultry farming to support her family during the current food crisis.

Please donate to Project Compassion 2023

Together, we can help vulnerable communities face their challenges today and build a better tomorrow **For All Future Generations**. You can donate through Project Compassion donation boxes available from your parish, by visiting caritas.org.au/project-compassion, or by calling 1800 024 413.



Living wisely means being mindful of our choices, actions and words. It means taking responsibility for our own happiness and well-being while also considering the impact we have on others and the world around us. It's about finding a balance between our own needs and the needs of others and making decisions that align with our values & goals.



Dear God, Grant me the wisdom to make the right choices in life. Help me to be mindful of the consequences of my actions and to always strive for what is good and just. May I live my life with purpose and meaning, and may my decisions be guided by your grace and wisdom. Amen.

Trace the journey of Jesus from the land of his birth to the way he carried his cross and gave the eternal sacrifice in this 14-day Holy Land pilgrimage to Jordan & Israel led by Fr Salas Muttathukattil MSFS. This pilgrimage features places from the Old & New Testament and includes Petra, Mt Nebo, Bethlehem, Nazareth, Sea of Galilee, Mt Sinai and Jerusalem for an all-inclusive offer of \$6,940 AUD. The fare includes Airfare + Local Transfers in Deluxe Coaches + Stay in Premium Hotels + All Breakfasts & Dinners + English speaking professional guides. Departure from Sydney and Melbourne on 21st May 2023. For inquiries & bookings call 1300 721 561 or email us info@magiholidays.com.au



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I made the decision that Niamh and I would go to America to find out more.

My beautiful sisters Jane and Louise and their spouses Mark and Todd organised a Trivia Night to raise money to get us there, while my place of work, Crown Casino held a fundraising morning tea. A colleague at Crown organised a Go Fund Me page as well and the money raised ensured that Niamh and I, as well as Jane, Mark and Seb could travel to the US to find out more, have further testing completed, and attend a conference on rare diseases.

GM1 Gangliosidosis, or Landing disease, is a rare inherited neurodegenerative lysosomal storage disorder characterized by severe cognitive and motor developmental delays resulting in the death of most patients at a very young age. It is caused by mutations in the GLB1 gene, which encodes an enzyme called beta-galactosidase necessary for the recycling of a molecule (GM1-ganglioside) in neurons. This brain lipid is indispensable for normal function, but its overabundance causes neurodegeneration, resulting in severe neurological symptoms. Children who suffer from GM1 face the progressive loss of skills and abilities. GM1 is a fatal disease that currently has no effective treatment nor cure.

Part 4 next week

