



Tribute to Sister Julie Thomas CSB OAM

3 January 1940 – 6 February 2023



With great sadness we wish to inform that our dear founder, past President, mentor, guiding light and great friend Sister Julie Thomas CSB OAM, passed away on Monday 6th February 2023 after a sudden deterioration in her health.

We know that many of you who were close to Sr Julie will feel a deep sense of sadness and will miss Sr Julie's compassion, friendship, wisdom, leadership and courage.

Sr Julie will forever remain in our hearts and minds for the strength and support she provided to those affected by leukodystrophy both personally and through founding Leukodystrophy Australia.

In her honour and memory, we will strive to continue her mission and vision:

- to provide compassionate assistance and information to those affected by Leukodystrophy,
- to continue to grow as the Australian support organisation for those affected by Leukodystrophy
- to increase public awareness about Leukodystrophy
- to strengthen our national and international links with like organisations.

Sr Julie was an amazing and humble woman. Her life story and unrelenting dedication to those living with leukodystrophy conditions has touched all who knew her. While we all share our own personal memories of Sr Julie, we have drawn from our archives to revisit Sr Julie's life and some of her core achievements.



Sr Julie's Life Story



Sr Julie, sister Janet and brother Alan

Sr Julie began her life in Moulamein NSW, before moving with her family to Echuca in Victoria and then to Melbourne to complete her schooling. She was the fifth child in a family of six, having had two older twin sisters who died shortly after their birth and two brothers, Alan and Barry, who died at the ages of 17 and 11 years. At the time of Barry's passing both of Sr Julie's brothers were thought to have died from the same unknown disease. Sr Julie enjoyed a close relationship with her much loved older sister Janet, until she passed away in 2022.

"I loved children, so I selected the teacher training course... I saw the children as 'little flowers' who grew and bloomed over the years"

Sr Julie



Sr Julie as a Postulant with her sister Janet

multiple sclerosis. She was later told in 1985 that she did not have MS, however her neurologist was unable to provide a diagnosis. The technology was not available at that time to diagnose leukodystrophy.

Sr Julie joined the Brigidine Sisters as a Postulant in 1957 and trained as a primary school teacher. She later became Principal of several primary schools including Springvale, Mentone, Mordialloc, Kyabram, Wangaratta, and Clayton in Victoria and Windsor Gardens in South Australia.

Sr Julie experienced health and mobility issues during her adult years and in 1984 was misdiagnosed with

Sr Julie continued her teaching until 1986 when her declining health situation, decreased mobility and poor balance made teaching difficult for her. She then attended a three month sabbatical in New Zealand and studied Pastoral and Spiritual Leadership which was followed by her return to Melbourne.

During this period, Sr Julie's mobility continued to deteriorate and in 1988 she was referred to Professor Ed Byrne at St Vincent's Hospital. Here she underwent a multitude of tests and was diagnosed

with Adrenomyeloneuropathy (AMN). Professor Byrne explained that her two brothers had inherited the dominant gene from their mother and had died from Adrenoleukodystrophy (ALD). Sr Julie remained under the care of Professor Byrne for many years, and he became her mentor in leukodystrophy conditions, research and management.

In 1991, Sr Julie was referred to Professor Hugo Moser from the Johns Hopkins Hospital in Baltimore (US), who was the renowned authority in ALD/AMN and other leukodystrophy conditions. She was invited to travel to the US as a 'research patient' of Professor Moser and during that trip she attended a leukodystrophy conference held through the US based United Leukodystrophy Foundation (ULF). She was greatly impressed with the way parents of children with leukodystrophy, adult sufferers and medicos, gathered and consulted together at that conference. Sr Julie would later recount that her experience of attending the ULF conference left her with a "strong feeling and urge that kept telling me...if they can do this in America, I am going to try and do something in Australia".

During the same trip, Sr Julie joined a medical trial of the well-known and strict ALD/AMN diet and commenced therapy of high doses of the medication known as Lorenzo's Oil. She remained on this strict regime for two years. Unfortunately, she didn't experience positive benefits from the treatment and ceased the trial under the agreement of Professor Moser and Professor Byrne in 1993.

On 17 August 1992, Sr Julie and her small team of committed volunteers and friends officially launched the Australian Leukodystrophy Support Group Incorporated

"Each religious order has its own motto. The Brigidine motto is 'strength and gentleness' upon which the life of this Catholic Order is followed"

Sr Julie

“We have the most incredible people who do extraordinary things in support of us, and the individuals and families we care for”

Sr Julie

with Sr Julie and ALDS as skilled and caring volunteers and fundraisers for many years to assist people affected by the disease.



Sr Julie with Janet and her Order of Australia Medal

(ALDS) at St Vincent’s Hospital, Melbourne. This event was attended by Professor Moser and his wife Anne. It drew and encouraged a wide number of supporters, many of whom continued to work

On Australia Day in 2001, Sr Julie was awarded the Order of Australia Medal (OAM) for service to the community, particularly as the Founder of the Australian Leukodystrophy Support Group Inc. This award was a great honour for Julie.

Over the years ALDS financed and held several significant conferences and seminars, both medical and scientific including:

- *Living with Adrenomyeloneuropathy Seminar* (Melbourne, 2002)
- *Diagnosis and Care – Increasing Hope Through Sharing Information and Knowledge Conference* (Melbourne, 2004)
- *Finding a Diagnosis for Leukodystrophies – The effect of AMN on Men* (Seminar, 2007)
- *1st Australian MLD Foundation Family Conference* (Preston, 2011)
- *ALDS 20th Anniversary Leukodystrophy Conference: ‘Honouring the Past, Celebrating the Present, Facing the Future Together’* (Melbourne, 2012).

In 2009, Sr Julie celebrated her Golden Jubilee: 50 years professed as a Brigidine nun. She moved into the Mary McKillop Aged Care facility in Hawthorn the following year after she suffered further deterioration in her health and mobility. She remained strongly involved and committed to the Australian Leukodystrophy Support Group and to people affected by the disease.



Sr Julie remained living and being beautifully cared for at her Mary McKillop home. On 22nd August, 2022, the 30th Anniversary event for Leukodystrophy Australia (previously known as ALDS) was held at the Mary McKillop home. The celebration was attended by many of Sr Julie’s long-term and dear friends, including her Brigidine Sisters, ALDS supporters and volunteers, and her friends and carers from the Mary McKillop home. It was a heart-warming and beautiful event to celebrate the amazing achievements of Sr Julie in her work and commitment to people living with leukodystrophy.

“We live in hope that one day medical research will find the answer to save the lives of those stricken with Leukodystrophy”

Sr Julie



We will all miss Sr Julie terribly and we will continue her mission to grow Leukodystrophy Australia as the peak body and support group for people living with leukodystrophy within Australia.

Information contained in Sr Julie’s Life story in this document is attributed to the following publications:

Sr Julie Thomas (2001) *As It Is – Those touched by Leukodystrophy – Sister Julie’s Story pp 4-6* Australian Leukodystrophy Support Group Inc
Sr Julie Thomas (2016) *Biography of Sr Julie Thomas CSB OAM* – Leukodystrophy Australia