Sister Julie Thomas
CSB OAM

SISTER JULIE THOMAS OAM, CSB

Preface

This biography relies on the generosity of Sr Julie Thomas, the first person diagnosed with Leukodystrophy in Australia, and the Founder of The Australian Leukodystrophy Support Group (ALDS), now known as Leukodystrophy Australia. She is living in Victoria, thus Sister Julie’s story tends to be focussed in Victoria, although families right across Australia were supported over the phone, and for a very long time, all the while managing her own disability, she managed to travel to all states except Northern Territory visiting families.

Sr Julie's biography is not only important to her family but also to all those people inflicted with this catastrophic disorder and to their families. She voiced her desire to record her life story for the Australian Leukodystrophy Support Group/Leukodystrophy Australia www.leuko.org.au and for the benefit of the families of those who suffer and have suffered with this terrible disease. She initially thought it would be wise in her biography to avoid the common introduction of birth, family, schooling and those of her other aspects common to everyone and simply to tell the story of the development of the Australian Leukodystrophy Support Group Inc. However, it was pointed out to her that all readers of this biography would be interested in all the features of her life leading to her wisdom in founding the ALDS. Sr Julie agreed to follow this suggestion.

The disease of Leukodystrophy has puzzled the medical experts. The conditions and expression of the different types of the disorder are emerging as identification of the various features is researched. The following information describing the disease has been sourced from the United Leukodystrophy Foundation USA www.ulf.org[1], the American organization that supports those with the disease and the Australian Leukodystrophy Support Group[2].

1. United Leukodystrophy Foundation USA, www.ulf.org
2. Leukodystrophy Australia, www.leuko.org.au
3. The Order of St Brigid

Introduction

In Sister Julie's own words:

My name is Margaret Mary Thomas. I am a Brigidine Nun[3] and I entered this Order as a Postulant on 31st January 1957.

At the time of recording this I am now 76 years old. As a nun I am known as Sr Julie. My reason for sharing my biography is because I myself have Leukodystrophy, a particularly horrible condition, and because of my deep involvement being the founder of The Australian Leukodystrophy Support Group Inc. - now Leukodystrophy Australia. There is as yet no cure or treatment for Leukodystrophy and the progress of the disease may be brief or prolonged, commencing anywhere throughout a patient's life. Leukodystrophy is an unusual genetic disorder, resulting from the mutation of the person’s genes that leads to one of around forty-two currently known types of the condition and many other unknown yet to be named types. It is not yet known how or why this genetic disorder should occur, and why it has similarities with other conditions that affect nerve and body functions.

Family, Religious Training and Teaching history

Continuing in her own words: Even though my family lived on a farm 10 miles out of Moulamein, a country town near Deniliquin in NSW, not far from Swan Hill, I was born in Melbourne, in January 1940. My mother had travelled to Melbourne to stay with her own mother and sister who lived in Elwood, to await my birth. Before we returned to our home in the country I was baptised at St. Columba's Church by the Parish Priest, at that time Father Greenan. The story is told that I cried very loudly while the baptismal water was being poured on my head. Apparently it was remarked that I wanted to be heard right from the beginning. I did however enjoy singing and strangely enough, I studied it as a subject for my Leaving Certificate!

Above: Julie 1944

Julie’s parents Mr Frank & Mrs Elizabeth Thomas

My family consisted of an older brother, Alan, a sister Janet, now Janet Hudin, who lives in Camberwell, (nearby to the Mary MacKillop Aged Care Home where nowadays I live), myself and brother Barry, four years younger. Before my birth twin girls were born who did not survive by more than a few days as a result of the less advanced medical knowledge of how to treat my mother's kidney condition 70 odd years ago.

When it was time for me to begin school, we moved to Echuca. I began at St. Joseph's College where the Brigidine nuns taught. I later finished school at Kildara Malvern, another Brigidine College. My older brother Alan, became very ill and received medical assistance in Melbourne until he died in The Caritas Christi Hospice in 1945. Ten years later my younger brother Barry, aged eleven, died from the same condition, also at Caritas Christi.

Alan, Janet and Julie – 1942

Barry aged 10 in Orrong Park

As a child I always had perfect health and loved swimming, bike riding and tennis. My mother lived until 1988, but my father died earlier in 1957, which was a great shock to me. 1957 was also the year I entered, and our Brigidine rule meant that I was not permitted to attend his funeral. However, I was able to attend his Requiem Mass at Our Lady of Lourdes Church Armadale.

Sr Julie's Grandmother Mrs Jane Daly, with Julie
and her mother Mrs Elizabeth Thomas - March 1957

Each religious order has its own motto. The Brigidine motto is *"strength and gentleness"* upon which the life of this Catholic Order is followed. Although this was hard initially for me, as a young girl, I had my loving mother's model in self-control behind me, as well as support from my family and the nuns. As a Brigidine nun I was offered the choice of training to become a teacher, or to undertake house duties. I loved children, so I selected the teacher training course, a two-year program that led to my certification for teaching Primary School children. During this training period of a couple of years, I became great friends with other trainees who have remained close friends ever since. Although I loved children, I found the training demanding and challenging. Fortunately, the friendly company made this easier and less stressful. To our amusement,we were each called funny names, such as "Gertie Snooks" if we didn't have an assignment in on time.

Janet Hudin with Sr Julie as a Postulant

Kaye Rogan with Sr Julie as a Novice

I was professed as a Nun with eleven other novices on 12th December 1959. After that I was moved to live in a convent at Springvale. My first teaching appointment was to St Joseph's Primary School from February 1960 until 1962. The children in this school were from Italy and Malta as well as Australia and were wonderful, happy little people. Many of them have kept in touch with me over the years, even now. At the end of the third year I was asked to transfer to Mentone, and to teach at the Saint Brigid's Primary School in Mordialloc. I taught in the different grades of Prep, and Years 1 and 2. I saw the children as "little flowers' who grew and bloomed over the years I was there, 1963 to 1967. About forty nuns were living in our Mentone Community, as well as boarders at Kilbreda. Added to our teaching were "boarder" duties related to the boarders' recreation and study times, supervising the dining room and the meeting of bedtime timetables.

Following this experience, I was transferred to Adelaide, to a Primary School, namely St Pius 10th in Windsor Grove, Windsor Gardens. This was such a change. I knew no one in Adelaide and felt very alone. It was during this period my sister Janet married Sven and I attended their wedding back in Melbourne. I thought the names of the suburb and the school sounded palatial, but in reality it was very poor. Our convent was built as a "roundhouse" where we were accommodated. This led to the opportunity for us to develop many friendships, which have persisted over all the years since. Many still keep in touch and some come to see me. I was transferred into Holden Hill where there is a

Secondary College called Kildare but I remained Principal, teaching at St Pius 10th Windsor Gardens. At that time, since Adelaide was very hot, the nuns were permitted to change from their all-black habit into white – a welcome change. I was appointed Principal at St Pius 10th Primary for the last five years, which I thoroughly enjoyed. However, following this time in Adelaide (1968-1976), when I was offered the opportunity to return to Victoria, where my mother and sister were living, I accepted.


Janet & Sven Hudin married 26 Nov 1971

My subsequent appointment was to the St Augustine’s School, a co-ed school, in the very small township of Kyabram, a centre for fruit and vegetable and dairy farming. The school timetables developed to fit with the times of the farming schedules, especially on sports days when the school had to fit around the cow’s milking hours. The farmers’ schedules needed to be treated with respect. It also altered other school customs – such as: no margarine on school lunches when “butter is better!”. As my original childhood farming experience was of my father growing crops and sheep, not fruit and dairy, I learnt to adapt, and enjoyed this area very much. Many times we received boxes of fruit, fresh and preserved, from grateful parents.

After two years in Kyabram 1976-77, I sought to upgrade my qualifications to a Diploma of Teaching through further study for another year at the Mercy Teacher’s College in Ascot Vale, in Melbourne in 1978. The College was training teachers ranging from those just finished school to the experienced teachers seeking further study such as myself. The upgraded training led to my appointment as Principal of Saint Bernard’s Primary School in Wangaratta initially, in 1979, and then to Principal of St Peter’s Primary School, Clayton, in Melbourne for five years, 1981 to 1986. It was there that the school population was again largely multicultural, so that the joke was, in the street, “spot the Aussie”.

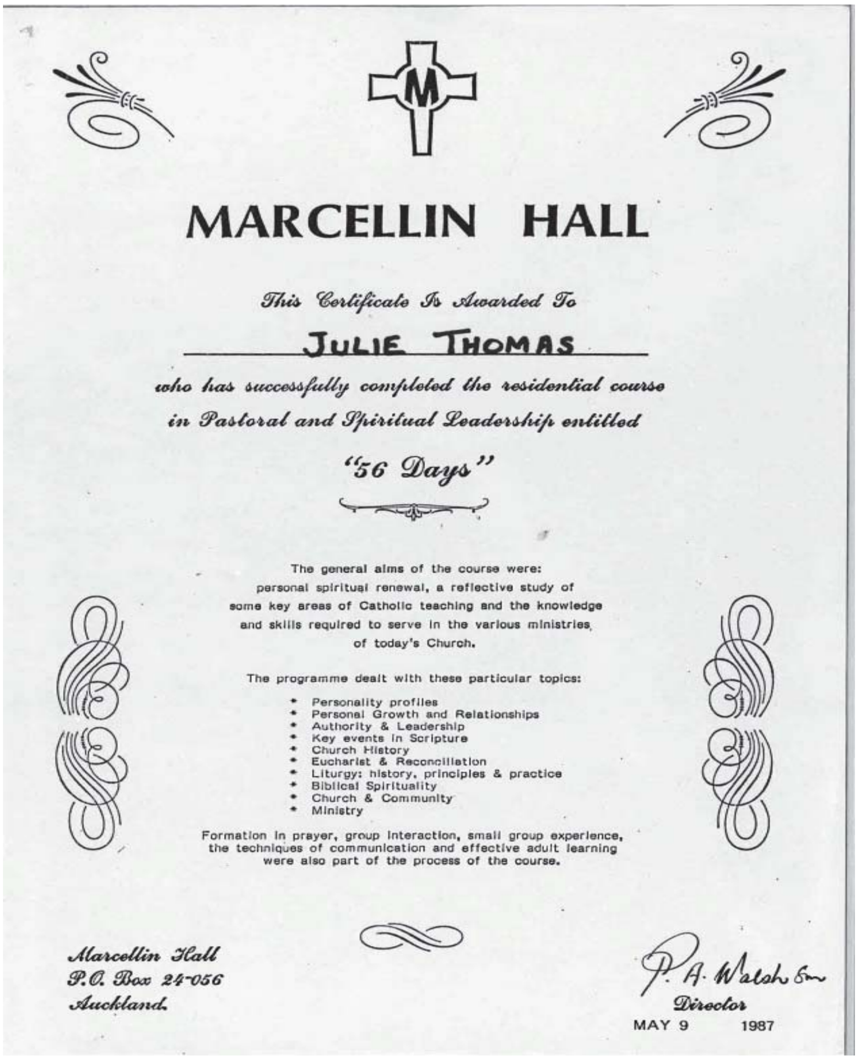
In 1986 my declining health made teaching difficult. I underwent many tests under the supervision of a neurologist at the Royal Melbourne Hospital. A mystery diagnosis followed these examinations but didn’t resolve anything. In 1987 I was offered a Sabbatical Leave in New Zealand.

Teaching is not an easy “9 to 4 job”. Consequently, the three months’ physical break from teaching in New Zealand gave me opportunity to attend a most rewarding spiritual course with the Marcellin Brothers. This was undertaken at Marcellin Hall, Auckland, where I was awarded a certificate in Pastoral and Spiritual Leadership.

In that same year, at least forty of us, many of us nuns, attended a 30-day retreat at a centre, known as St Ignatius in Pymble. We were enriched by this opportunity to renew and strengthen our faith and prayer life.

L to R

St. Peters Primary School 1985 Staff



MARCELLIN HALL

This Certificate Is Awarded To

JULIE THOMAS

who has successfully completed the residential course in Pastoral and Spiritual Leadership entitled

"56 Days"

The general aims of the course were: personal spiritual renewal, a reflective study of some key areas of Catholic teaching and the knowledge and skills required to serve in the various ministries of today's Church.

The programme dealt with these particular topics:

- Personality profiles
- Personal Growth and Relationships
- Authority & Leadership
- Key events in Scripture
- Church History
- Eucharist & Reconciliation
- Liturgy: history, principles & practice
- Biblical Spirituality
- Church & Community
- Ministry

Formation in prayer, group interaction, small group experience, the techniques of communication and effective adult learning were also part of the process of the course.

Marcellin Hall
P.O. Box 24-056
Auckland.

P. A. Walsh
Director
MAY 9 1987

Certificate awarded at Marcellin Hall, New Zealand, 1987

Fellow participants at Marcellin Hall, NZ 1987

Members of our retreat at St Ignatius, Pymble NSW, 1987

Diagnosis of Sr Julie's of Leukodystrophy

Upon my return from New Zealand I sought further medical assistance. Although I was still driving a car with modifications to assist my driving skills, I needed an aid for walking. I was later admitted into St Vincent’s Hospital for two weeks for a biopsy, blood and neurological tests, under the supervision initially of Dr John Billings, who had attended my brother Barry, then later of Dr Ed Byrne. Dr Billings had not been able to diagnose Barry’s condition, as these technologies were not then available, although he did recognise that Barry’s brain showed signs of being affected and that his life would be short.

My initial diagnosis was as Multiple Sclerosis, but examination beyond this, with an MRI scan, led to a diagnosis by Dr Ed Byrne, of Adrenomyeloneuropathy AMN, a lengthy time later, possibly even a year! This MRI scan was with the first machine using that particular specialised technology to be installed in Victoria in the Royal Melbourne Hospital.

My brother Barry, as well as my older brother, Alan, was diagnosed after their deaths with the Adrenoleukodystrophy ALD, condition as the specialised technology was not previously available.

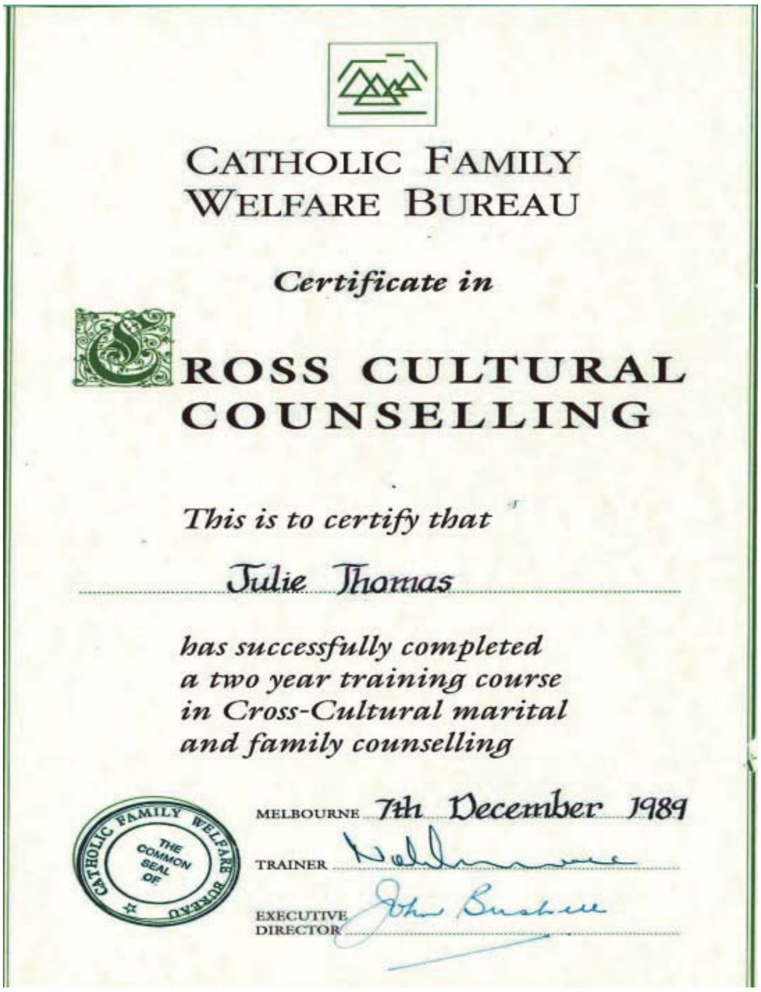
Dr, later Professor, Ed Byrne renewed my diagnosis to that of Leukodystrophy in 1988. Further blood testing analysis, which was undertaken at the Women and Children’s Hospital in Adelaide, confirmed Dr Byrne’s diagnosis. It was at this time that the contributing cause of Leukodystrophy was identified as a recessive gene on the X chromosome (called a ‘weak’ female chromosome). Dr Byrne explained how my brothers both had this recessive gene carried from our mother causing the neurological problem, whereas I have this recessive gene as well as a healthy, normal gene on my second X chromosome. This is possibly why my problem did not manifest itself until I was older. My sister Janet was examined and to my great relief, did not show any of the symptoms of the disease.

I was pleased my mother had died (in 1988) completely unaware of the cause of my condition. She had been distressed enough over the weaknesses in my mobility. When the Leukodystrophy disorder started outside my immediate family is still a mystery.

During this period of my mounting weakness I shared the medical developments with and was supported by, a very great friend, Kaye Rogan. She became a strong benefactor to those with Leukodystrophy and their families, and remains so to this day. There were many others who greatly assisted in support of me.

I had frequent physiotherapy and hydrotherapy. I also continued working in a small way in a couple of schools, and did some study into Counselling and Pastoral Care in 1989.

I was awarded a Certificate in Cross Cultural Counselling by the Catholic Family Welfare Bureau. Mrs Nada Miocevic, who trained those of us in this program, has been a volunteer counsellor for many years to ALDS. We have a strong friendship.



CATHOLIC FAMILY
WELFARE BUREAU

Certificate in

CROSS CULTURAL
COUNSELLING

This is to certify that

Julie Thomas

has successfully completed
a two year training course
in Cross-Cultural marital
and family counselling

MELBOURNE 7th December 1989

TRAINER

EXECUTIVE DIRECTOR John Bushell

The Award on completion of the Cross Cultural Counselling Program 1989

Cross Cultural Students Certificate Course with Mrs Nada Miocevic - 2nd row, 3rd left

About this time, in 1991, I was invited to America to be a Research patient in a study undertaken by Dr Hugo Moser, the world authority on the Leukodystrophy conditions, in Baltimore at the John Hopkins Hospital. As well as extensive testing of both neurological and genetic features of my condition, research into the value of Lorenzo’s Oil was underway. Dr Moser, who believed it was worthwhile to use the Lorenzo’s Oil diet, as it was unlikely to cause harm, and may contribute a benefit, introduced me to a diet of large doses of Lorenzo’s Oil. The trial did not achieve any benefit for me, therefore after a two-year trial the diet was discontinued.

Sr Julie and Sr Rosie Joyce in front of the Statue of the Irish Bishop Daniel Delaney, the Founder of the Order of St Brigid, erected in San Antonio, Texas, USA

Founding of the Australian Leukodystrophy Support Group

Sr Julie's 60th Birthday with Kaye Rogan

Whilst in Baltimore I attended the Leukodystrophy Foundation Conference in DeKalb, a city within Chicago Illinois. The United Leukodystrophy Foundation (ULF)[1] supports those patients with Leukodystrophy and their families in USA. Arising from these experiences in Baltimore, and discovering the role of the ULF as a support for Leukodystrophy sufferers in the USA, I sought through prayer to find a way to use my time to do something similar in Australia.

By 1992, with the help of others associated with this terrible disease, we worked out a logo and the opportunity to support a Leukodystrophy group. On 17 August 1992, the Australian Leukodystrophy Support Group Inc. (ALDS)[2] was launched at St Vincent’s Hospital in Melbourne. Dr Moser and his wife, Ann, who were attending a medical conference in Australia, joined us for the celebration of the new ALDS establishment.

This event encouraged a wide number of supporters, many of whom have remained as volunteers in the ongoing process of assisting those affected by the disease. It was a most encouraging beginning.

There many people from Echuca who gave me and ALDS so much help. There were many who had been at St. Joseph's College with Barry & me. When it was realised that Barry was unwell, and this was reason for our move to Melbourne in 1954.

Barry died in December 1955. Years later, in 1988, I was finally diagnosed with a Leukodystrophy. Naturally I found this particularly hard and somewhat lonely and was grateful for their ongoing friendship.

As already mentioned I was invited to travel to Baltimore as a Research Patient; when a few friends, as well as another couple, who had moved from Echuca heard this news, to my pleasant and grateful surprise, made a very generous donation towards this. One friend in particular was Therese Bourke (Monahan). Therese came to Melbourne to train as a nurse and she later married a doctor. I also had relations who have been and still are kind and generous to me and the Organisation. Naturally the nuns and my sister are likewise and I can't thank them enough.

I was greatly assisted with the growth and development of the Group in 2002 by the employment of Robyn Loh as a part-time secretary. Since we received no Government funding we had very little financial help; therefore, Robyn initially worked for about two days per week, offering great help and relief to me - I will never forget her great assistance!

We heard about the Melbourne Lord Mayor's Financial Award which if we made a suitable application (which we did) we'd receive a welcome and most helpful amount of money, permitting us to use it for a salary! We extended Robyn's employment. She was a beautiful and quiet worker and I would not have been able to keep going without her outstanding help for just near to ten years!

Robyn Loh and Sr Julie - 20th Anniversary Conference 2012 at the Novatel St Kilda

When Robyn informed me she was unable to continue as my Office Manager, I was very upset and most distraught. I thought to myself I could not continue with these responsibilities accompanied by my disability. Advertising in the local newspapers led to the appointment of one who was found to be not suitable to continue in the position, as well as a sequel of others, also unsuitable.   I managed alone for a while with the occasional help from a volunteer or two, until Bronwyn arrived. She had previously assisted as a volunteer, and was appointed, overcoming competition from numerous aspirants.

Bronwyn Byrne and Sr Julie working on the Biography 2016

We had some outstanding Treasurers who greatly helped lay the foundations with me in those early years and well beyond: Brian Keable, Bernadette Toohey and Anthony Laragy till 2010.

1: Brian Keable. Brian was initially on the Committee for a short time. He was the father of Janet McGarry who had twin children, Natalie & Nathan. Sadly, Natalie was diagnosed with MLD, while Nathan was free of this condition.

Brian soon understood we needed a Treasurer and he volunteered to take on this position. Both he and his wife Norma, worked very hard in raising funds because when the ALDS/Leukodystrophy Australia began in 1992 money was not plentiful.

Brian did the books & presented everything very carefully at the monthly Committee meetings & of course at the yearly Annual General Meeting. When Brian felt the need to retire, not very long after Natalie died, there was the great need for a replacement.

2: Bernadette Toohey. It was fortunate that not too long after Brian resigned that I had met Bernadette, a young married lady from Adelaide and a past pupil of mine who lived and went to school in Adelaide. Fortunately, we remembered each other & Bernadette had gone to university & studied to become an accountant. The man she married was also an accountant. When I asked Bernadette if she would consider taking on this voluntary position, to my delight she agreed!

She was and is a most intelligent woman in being an accountant & she spent many hours in filling this position. I know all who were on the Committee were more than grateful for Bernadette for her professionalism. She resigned when she was expecting her 3rd child, but to those who knew her, she was never forgotten & we will be forever grateful.

3: Anthony Laragy: I put a small advertisement for the position of Treasurer in a local magazine very near to where I lived. To my pleasant surprise & delight Anthony answered this advertisement. He had retired from a senior position with the PMG.

Following an Executive Committee meeting and a brief interview, Tony was invited to fill this role which he did in a professional and dedicated manner. He had some wonderful ideas and always had a very friendly manner. Tony retired when I retired in 2010.

Graham Cadd who has a son suffering from AMN was on the ALDS Committee for quite a number of years. He was a very keen bike rider. He cycled from Perth to Byron Bay as a fundraising activity on three different occasions, together with some of his friends who were very happy to ride as companions. In some areas they rode when weather was very inclement and dangerous. Despite these conditions in each year they raised about $25,000. This was an enormous help to the ALDS and all involved!

Even now in 2016, John Olsen who is one of our three Ambassadors, began his third walk across Australia www.leuko.org.au, the first being in 2002, to raise much needed funds for our group in support of families living with Leukodystrophy. He is unaccompanied by any support vehicle. John's second walk was in 2008. His dear partner, Vida passed away in February 2014. We have the most incredible people who do extraordinary things in support of us, and the individuals and families we care for.

Our other two Ambassadors are Gary Dawson OAM and Matthew Laverty of The Charity Challenge[5]. Through their golf days we have benefited greatly and it would be fair to say without our Ambassadors Leukodystrophy Australia would not exist today.

[5] www.thecharitychallenge.com

Over the years we held several significant Conferences and Seminars, both Medical and Scientific:

- **Living with Adrenomyeloneuropathy (AMN)**
  25 October 2002, Melbourne, MS Nerve Centre, Blackburn.
  This free seminar was financed by the ALDS and was open to interested health professionals and ALDS Members

- **The Australian Leukodystrophy Conference 2004 Diagnosis and Care: Increasing Hope Through Sharing Information and Knowledge**
  25 October 2004 Royal Children's Hospital Melbourne

- **AUGUST 2007 MELBOURNE SEMINAR**
  Finding a Diagnosis for Leukodystrophies: The effect of AMN on Men- 1st Australian MLD Foundation Family Conference
  19 March 2011 at Ridge’s Bell City Conference Centre

- **20th ANNIVERSARY LEUKODYSTROPHY CONFERENCE MELBOURNE**
  20 YEARS OF ALDS: 'Honouring the Past, Celebrating the Present, Facing the Future Together'
  18 & 19 August 2012

Sr Julie – 20th Annual Leukodystrophy Conference 2012

Following my retirement Leukodystrophy Australia has since held another significant event which was rather special as it was held in Western Australia, thanks to our WA Committee Member Angela Famiano - **The WA Family Forum & Fun Day**. This event was held at Mangles Bay Fishing Club where many families attended, together with significant guest speakers from related service providers. I believe it was a day to remember.

Information regarding the current operation of the Australian Leukodystrophy Support Group Inc. - Leukodystrophy Australia since August 2015, can be accessed via
www.leuko.org.au or through an email request:
info@leuko.org.au

Above and below Sisters of the Order of St Brigid who were professed in 1959 meeting together in later years

Queen Elizabeth OAM Award - Order of Australia Medal by the Governor of Victoria

On Australia Day 2001 I was honoured with the presentation of an Order of Australia Medal, OAM, for “service to the community, particularly as the Founder of the Australian Leukodystrophy Support Group Inc.”

Sir John Landy, Governor of Victoria made the investiture at Government House, Melbourne. My sister Janet Hudin and a number of special friends were invited to be present at the ceremonial celebrations. These included Ruth McGowan, the Vice-President of the ALDS at the time, and Sr Bernadette Nihill who was a member of the Brigidine Mentone Community, where I was living. I am proud to have been honoured with this award.

Sr Julie is awarded the Order of Australia by Sir John Landy Governor of Victoria on Australia Day 2001

William Deane

Governor-General of the Commonwealth
of Australia and
Chancellor of the Order of Australia

To

JULIE THOMAS

Greeting

NOW KNOW YOU that, with the approval of Her Majesty Queen Elizabeth The Second, Queen of Australia and Sovereign of the Order of Australia, I have been pleased to award you the Medal of the Order of Australia in the General Division.

I DO by these Presents authorise you to hold and enjoy the dignity of such an award together with membership in the said Order and all privileges thereunto appertaining.

GIVEN at Government House, Canberra, under the seal of the Order of Australia this twenty-sixth day of January 2001.

By His Excellency's Command

Secretary of the Order of Australia

Government House, Victoria – Julie, Janet Hudin, Ruth McGowan, Lady Lyn Landy celebrating

Janet & Julie celebrating The Australia Day Award 2001

Conclusion

Continuing in her own words: I wish to conclude with the reasons of when and why I came to live at Mary MacKillop Aged Care, East Hawthorn, Melbourne. On Christmas Day afternoon in 2010, I drove myself to my sister Janet's home where I was to stay with her for a few weeks' holiday. However, early in the New Year of 2011, after having celebrated my birthday and a film at the Rivoli Theatre in Camberwell, I became very unwell. Janet rang for an ambulance, which drove me to Epworth Hospital's Emergency Department in East Melbourne, where I was admitted to the nearby Freemasons Hospital. A Medical Team accompanied by Sr. Anne Boyd and Janet followed. As a patient there I very slowly recovered. It was decided however I needed further medical care, so I was transferred to St George's Hospital in Kew for Rehabilitation. After a few weeks I was referred for daily physiotherapy and exercise treatments. I gradually got to know these friendly people who with experience, patience and encouragement, assisted my recovery. As my physical condition improved, I gained more confidence. However, when it was time for me to leave St. George's Hospital, my senior Medical Advisor, our Victorian Brigidine Leader, Helen Toohey, our nurse Joy Groenewegen and my sister Janet, decided that it was unwise for me to remain living with the Mentone Brigidine Community where there was no high level medical care in place. Consequently, I was accommodated in the Mary MacKillop Nursing and Aged Care Home at East Hawthorn, where I am still. I am grateful to all those who assisted me to be admitted here on March 7th 2011. I continue to be cared for

in this very friendly environment and am happy to say, I enjoy the kind and very caring staff.
Conclusion of Sister Julie Thomas own words.

Sr Julie & Janet celebrating Golden Jubile in 2009 – 50 Years professed as a Brigidine nun

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Footnotes

1 www.Ulf.org

The United Leukodystrophy Foundation USA

What is Leukodystrophy?

The Leukodystrophies are a group of rare genetic disorders that affect the central nervous system by disrupting the growth or maintenance of the myelin sheath that insulates nerve cells. These disorders are progressive, meaning that they tend to get worse throughout the life of the patient. The information below describes the disorders in more detail. Fact sheets on the individual Leukodystrophies are also available from the United Leukodystrophy Foundation – www.ulf.org

The word Leukodystrophy comes from the Greek words leuko (meaning white), trophy (meaning growth), and dys (meaning ill). Putting these pieces together, the word Leukodystrophy describes a set of diseases that affect the growth or maintenance of the white matter (myelin) insulating the nerve fibre – the neuron.

What is the nervous system?

In order to understand the Leukodystrophies, we need to discuss some basic facts about the nervous system. The nervous system is made up of two main components: the central nervous system (CNS) and the peripheral nervous system (PNS). Together, these two systems interact to carry and receive signals that are responsible for nearly everything we do, including involuntary functions such as our heartbeat and voluntary functions such as walking. The CNS consists of the brain and the spinal cord and contains billions of specialized cells known as neurons. Neurons have specialized projections called dendrites and axons that contribute to their unique function of transmitting signals throughout the body. Dendrites carry electrical signals to the neuron, while axons carry them away from the neuron. The PNS consists of the rest of the neurons in the body. These include the sensory neurons, which detect any sensory stimuli and alert the CNS of their presence, and motor neurons, which connect the CNS to the muscles and carry out instructions from the CNS for movement.

What is Myelin?

Myelin, sometimes referred to as “white matter” because of its white, fatty appearance, protects and insulates the axons. It consists of a protective sheath of many different molecules that include both lipids (fatty molecules) and proteins. This protective sheath acts in a manner very similar to that of the protective insulation surrounding an electric wire; that is, it is necessary for the rapid transmission of electrical signals between neurons. It does this primarily by containing the electrical molecules within the axon so they are all properly transmitted to the next neuron. With the protective myelin coat, neurons can transmit signals at speeds up to 60 metres per second. When the coat is damaged, the maximum speed can decrease by ten-fold or more, since some of the signal is lost during transmission. This decrease in speed of signal transmission leads to significant disruption in the proper functioning of the nervous system.

How are the Leukodystrophies different from one another?

All Leukodystrophies are a result of problems with the growth or maintenance of the myelin sheath. However, there are many genes that are important in this process. For example, some genes are involved with the synthesis of the proteins needed for the myelin, while others are required for the proper transport of these proteins to their final location in the myelin sheath that covers the axons. Defects in any of the genes (called a mutation) may lead to a Leukodystrophy. However, the symptoms of the individual Leukodystrophies may vary because of the differences in their genetic cause. The specific Leukodystrophy is a consequence of the location of the mutation’s damage- such that an Adrenoleukodystrophy is a result of damage to the neurons serving the adrenal glands.

How do you get Leukodystrophy?

Leukodystrophies are mostly inherited disorders, meaning it is passed on from parent to child. They may be inherited in a recessive, dominant, or X-linked manner, depending on the type of Leukodystrophy. A fact sheet describing the different genetic inheritance patterns is available from the United Leukodystrophy Foundation www.ulf.org

The individual pages on each Leukodystrophy will describe the particular pattern of inheritance for that disease. There are some Leukodystrophies that do not appear to be inherited, but rather arise spontaneously. They are still caused by a mutation in a particular gene, but it means the mutation was not inherited. In this case, the birth of one child with the disease does not necessarily increase the likelihood of a second child having the disease.

Are the Leukodystrophies related to multiple sclerosis?

The Leukodystrophies do share some common features with multiple sclerosis (MS). Like the Leukodystrophies, MS is caused by the loss of myelin from the axons. However, the cause is different; whereas Leukodystrophies are generally caused by a defect in one of the genes involved with the growth or maintenance of the myelin, MS is thought to be caused by an attack on the myelin by the body’s own immune system.

How many different Leukodystrophies are there?

New Leukodystrophies are always being identified. The number currently identified is now fifty-two. Information on each of these is available from www.ulf.org

2. www.leuko.org.au

The Australian Leukodystrophy Support Group Inc.

now **Leukodystrophy Australia**

The organisation was founded by Sr Julie Thomas in 1992, who became its first President. She maintained

this position until her retirement, seventeen years later in 2010.
Leukodystrophy Australia supports individuals and their families across Australia, welcoming anyone who has had some kind of contact with Leukodystrophy either personally or through a family member or friend. Without government funding, a major role of the organisation is fundraising. This is done in various ways: grant writing, fundraising events and benefactors. We are extremely grateful to all these loyal and valuable people including our Ambassadors.

Together and over the years with our wonderful Presidents/Committees, Office Managers, Family Advocates and my dear friend Kaye Rogan we:

- Provide emotional and practical support to individuals and families.
- Provide information and advocacy.
- Provide professional liaison with local services (with consent).
- Provide up-to-date information via our website, newsletters, and social media.
- Link families with similar conditions or experiences for peer support.
- Raise funds to enable the members of ADLS to offer a range of supports to individuals and families, including access to equipment, services and financial aid.
- Support research, community education and awareness-raising.

Since ALDS inauguration, and with the initial endorsement arising from the visit in 1992 of Dr Hugh Moser from the John Hopkins Hospital in Baltimore, USA, Leukodystrophy Australia has held local conferences attracting into Australia international speakers. Many of these included neurologists as well as other practitioners in treating the condition. These conferences were held in Melbourne. Professional practitioners from Australia and Europe and USA were either invited or volunteered to attend.

For further information about Leukodystrophy Australia:

www.leuko.org.au or email info@leuko.org.au

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Registered Charity name - Australian Leukodystrophy Support Group Inc

3. The Brigidine Order

The Brigidine Sisters is a global Catholic congregation, founded by Bishop Daniel Delany in Mountrath, Ireland in February 1807. There were six founding members, all originally catechists: Eleanor Tallon, Margaret Kinsella, Eleanor Dawson, Judith Whelan, Bridget Brien and Catherine Doyle. In 1883, in answer to a request from a bishop in New South Wales, six sisters from Mountrath went to Australia. They founded their first convent in Coonamble, a country town in New South Wales in 1883. In 1886 the Brigidines's were brought to Echuca, on the Murray River in Victoria, where a Secondary School was established: St Joseph's College in the house of the Founder of Echuca, whose name was Henry Hopwood. This was our first school in Victoria. Brigidine nuns also staffed St Mary's Primary School in Echuca.

Establishment of new convents, many of them boarding schools, followed. In 1886 a Secondary School and a Parish Primary School staffed by Brigidine nuns were opened in Beechworth. In 1887 in Wangaratta a Secondary School and a Parish Primary School were also staffed by Brigidine nuns. In 1888 in Ararat a Secondary School and a Parish Primary School were staffed by Brigidine nuns and later in Rochester in 1893, a Secondary College and a Primary School. The above colleges were all staffed by the Brigidine nuns coming from Ireland. Over the years from 1902, other schools and colleges followed: in Maryborough, Kyabram, Mentone in 1904 (Kilbreda College our city boarding school), Albert Park in 1909, and Malvern in 1917. Many years on, Sunshine Secondary College, Sunshine West Primary School and Geelong Secondary College followed. From this rapid growth, branches quickly spread to the dioceses of Sydney, Canberra, Perth and Brisbane. There was also New Zealand, the Archdiocese of Wellington from 1898.

Here is a lovely and fitting quote from Sr Julie made at the time of her retirement:
“The disorder is devastating for families. Hearing the news, they just can’t believe it, they are in a state of shock, sometimes denial. I chose this time to retire because I know in my heart, the support group will continue to grow and be an effective resource for all families linked with it. Families will continue to be taken care of compassionately and respectfully - which is what they deserve."

Sr Julie, home at Mary MacKillop, Hawthorn East, Melbourne 2016


Mary MacKillop
Aged C

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