

# Kalparrin *Cares*

The Newsletter of  
Parents of Children with Disabilities (Inc)

September 2013  
Volume 10 Issue 2

## ***SHINING BRIGHT LIKE A DIAMOND*** *Mother's 60th Anniversary Weekend at the Hyatt*



***..families supporting families..***



## Parents of Children with Special Needs Inc.

### Board

<b>Chairperson</b>	Libby Lyons
<b>Vice Chairperson</b>	Fiona Payne
<b>Secretary</b>	Vacant
<b>Treasurer</b>	Shawn Pearson
<b>Committee</b>	Tracey Barnes
	Jenny Bourke
	Sarah Flanagan
	Beverley Gay
	Libby Lyons
	Shaun Murphy
	Amanda Reed

### Staff

#### Executive Chair

Libby Lyons

#### Family Support Officers

Leticia Grant

Lucy Moran

Leanne Bridges

#### Program & Events Coordinator

Cecilia Donovan

#### WA Special Families Program Manager

Anita Peiris

#### Business Manager

Eugene Mostovoy

### Editorial Disclaimer

*The **Kalparrin Cares** newsletter editors are not professional journalists and wish to advise that views expressed in articles included in this newsletter are not necessarily those of the editors, Parents of Children with Special Needs Inc.*

## In this Edition:

Executive Chair	3-4
ConnectGroups Award	4
A Kalparrin Review	4
Kalparrin Charter	5
Welcome New Kalparrin Staff	6
Kalparrin Events to Date	7-10
Kalparrin Upcoming Events	11-12
Speaking out about Disability	12
Members Matters	13
Kalparrin Calendar of Events	14
Introducing the PMH Linc Coordinator	15
Member's Story	16-18
Membership Application Form	19
Donation Form	20

Sharing stories and wisdom with other families is the essence of Kalparrin. If you would like to share your experiences in caring for a child with special needs, we would love to hear from you. Please send your stories to:

**[kalparrinwa@health.wa.gov.au](mailto:kalparrinwa@health.wa.gov.au)**



## **Libby Lyons Executive Chair**

---

I have always had the utmost admiration for journalists. I marvel at their ability to turn a blank page into an interesting and compelling story ... and they manage to do it on a daily basis.

So, as I sit here in front of a blank page trying to find interesting and compelling words to tell you all about our Kalparrin story over the last month, I will seek in advance, your patience with my inadequate journalistic skills!

I joined the Kalparrin Board in 2012. My main reason for joining was that I could see the “hole” that Kalparrin plugged in providing services for the many mums, dads, brothers, sisters and carers of our special children, in the community. Little did I know, when I made that commitment that I would in time take a hands on role – albeit for a short period of time – at Kalparrin.

This last month has been a whirlwind of activity. As well as my joining the team we have also welcomed Eugene Mostovoy. Like me, Eugene has joined us on a short term basis as Business Manager and has been working hard on streamlining our business and financial processes. As the only male in our office he has had, I think, a “baptism of fire”, but he’s settled in well and is now just one of us!

Another change has been that Cecilia Donovan has taken on the role as Events Coordinator. As you would be aware, this is a very important role at Kalparrin because we know the great value that you place on our weekends and events. But with Cecilia in the role we are in the most capable of hands. Take the time to look at our upcoming events on page 14 and put some plans in place, as we are looking forward to seeing you at one of our special events.

With Cecilia having taken on a new role we are currently looking at the hours of work for each of our Family Support Officers (FSO) Leticia Grant, Lucy Moran and Leanne Bridges. For anyone that has ever come into or rung the Kalparrin Office, or attended an event, you will know just how valuable and essential our FSO’s are to every member. The care, understanding, knowledge and support these wonderful people show everyday is without peer.

Another staff member, without peer, is Anita Peiris. Anita, as most of you will know, is the Program Manager / Coordinator of WA Special Families. This wonderful program and the tireless work Anita does in overseeing and coordinating it, means WASF is a leader in WA, and arguably Australia, in providing online support using social media.

We are all very excited at Kalparrin because Anita and WASF is a finalist in ConnectGroups 2013 Good Practice Awards. The Gala event at which the winners are announced is on 11<sup>th</sup> September and we will all be there cheering very loudly for her. We will keep you posted on the outcome! But whether she wins or not is immaterial, as we are just so proud of what Anita does, she is always a winner to us.

As well as staff changes, there have also been some Board changes. Should any of you have missed the email I sent out on this to the membership, it is on the Kalparrin website, have a read. In mentioning these changes, I would like to again thank the previous Chair and Board member Mr Ernest Boswarva for his steadfast contribution to Kalparrin. I know that I speak on behalf of all the Kalparrin family in thanking Ernest and wishing him the speediest of recoveries.

As the new Chair of the Board I feel very honoured to be working with such a dedicated and professional group of volunteers. Change is difficult for any organisation. However, the Kalparrin Board has embraced the changes we have experienced and the changes we face. The members of the Board work very hard to ensure that Kalparrin’s core business and services are maintained to the highest standard.

*Cont’d over*



---

## **Libby Lyons**

*(from page 3)*

So, I can assure you, that with such a hard working and dedicated Staff and Board, the future for Kalparrin is bright.

It is a future that is looking to reach out to our regional members to provide them with some of the quality services we provide in Perth. It

is a future that will continue to advocate and represent the interests of our members to the wider community, and it is a future that will give you some of what you so desperately need - TIME. Time to be YOU.

Thank you to all who have made me feel so welcome in my first few weeks and I look forward to meeting many of you soon.

---

## **Anita Peiris Wins the ConnectGroups Award for Effective Use of Social Media**

---

### ***Breaking news:***

The night before this edition of Kalparrin Cares went to print ConnectGroups held its 30<sup>th</sup> Year Anniversary and “Recognising Good Practice” Gala Night. We were thrilled to witness the award for Effective Use of Social Media to go

to Anita Peiris, Kalparrin’s own Program Manager for WA Special Families!

In her brief acceptance speech Anita acknowledged that it was an award in fact not only for her but for the whole team of WASF regional leaders and administrators.

---

## **A Review of what we do and how we tell it**

---

We are delighted to announce we are now engaged in a project with communications agency Groves & Groves, to review a better understanding of what Kalparrin means to our members and the wider community and how we can better tell our story to everyone. Through Groves & Groves we will be actively seeking to understand the views of our members and stakeholders in regard to our organisation, brand and services.

Groves & Groves may contact some of you over the coming weeks to seek your input.

There will of course be the option to contribute or opt out should you be contacted. We will also be sharing updates via the Kalparrin website and WA Special Families (WASF), providing the opportunity for those who wish, to contribute by responding to some important questions we will be asking about Kalparrin.

We really look forward to hearing from you and sharing updates with you as the project progresses and ultimately unveiling the story for the next part of the Kalparrin journey.





Please remember that in signing up and renewing your Kalparrin membership you agree to abide by the Kalparrin Membership Charter

## MEMBERSHIP CHARTER

***As Kalparrin members, carers and families have the right to:***

- information, resources and referral to services;
- access respite events;
- receive quarterly newsletters;
- use the Kalparrin drop-in centre and Parent lounge;
- access the Kalparrin website and interactive forums;
- be treated with respect and dignity;
- privacy, dignity and confidentiality; and
- an effective, efficient, prompt and courteous service from Kalparrin employees.

***As Kalparrin members, carers and families have a responsibility to:***

- be courteous to and respect the roles of the Kalparrin employees;
- tell Kalparrin employees about any concerns they have;
- respect the privacy, dignity and confidentiality of other Kalparrin members;
- avoid speaking on behalf of Kalparrin members without prior authorisation;
- protect and promote the good reputation of the Kalparrin members; and
- behave ethically and with integrity as a member of Kalparrin.



# Kalparrin Annual General Meeting

---

Parents of Children with Special Needs Inc. (Kalparrin) will hold its Annual General Meeting on Wednesday, 30<sup>th</sup> October 2013. An official AGM notice with time, venue details and other meeting particulars will be sent out to current Kalparrin members in the coming weeks.

---

## Kalparrin Welcomes New Staff

---

Eugene Mostovoy

Business Manager



I bring to Kalparrin over 15 years of experience in strategic management, HR, marketing, organisational change, and efficiency improvement. I have spent most of my career in a business environment, and I am happy to apply some good practice principles in the not for profit sector. My goal at Kalparrin is to establish a solid foundation for sustainable development of programs that support families of children with special needs across Western Australia.

Leanne Bridges

Administration / Family Support Officer



I am a mother to two children, my son Hunter and my daughter Ella, who has an intellectual disability. I have a long history with Kalparrin. I have been a member for 8 years, worked and volunteered in the office and served on the Board as Secretary and Vice Chairperson. I retired from the Board in April 2012 but continue to support Kalparrin in many and varied ways. I'm back in the office now as Family Support and Administration Officer and I'm loving it. My passion for Kalparrin is a constant and I am committed to the exciting future ahead.

# Kalparrin Events

---

## Mothers 60<sup>th</sup> Anniversary at the Hyatt

On the weekend of the 8<sup>th</sup>/9<sup>th</sup> June, Kalparrin hosted its 60th Mothers weekend at the Hyatt. It was the anniversary of the very first Kalparrin Mothers weekend, which was held on that exact weekend in 1983. The theme was "Diamond Celebration" and it most certainly was.

The weekend started Saturday morning with everyone arriving to participate in the many activities that were planned. There was interesting information and discussion had around the NDIS, (now Disability Care) from Ron Chalmers, Director General of DSC. Barbara Oosterhuis from Community Living and Participation Grants, gave us some invaluable information and advice around applying for grants, anything from dance lessons for your child with special needs to weekends away with like minded souls needing a break.

We then had Click Colours put on a presentation 'Why we click with some people and not others' that was both extremely interesting and really good fun.

To get everyone moving we had Belly Dancing, both liberating and fun and Yoga which is as always a great way to wind down, there was more than one of us snoring by the end!

Saturday night.....'Oh what a night'.....it was a glittering, fun and an all round fantastic night. Raffle prizes galore and a special gift for 20 lucky mums. Nineteen sterling silver and simulated diamond necklaces and one real silver and diamond necklace, were given away in a 'pass the parcel' game during the night. The winners were delighted with their prizes and it added to an already spectacular evening.

The Greg Schultz Band was the entertainment for the night and they gave a fantastic performance. There were many sore feet by the end of the evening, so much dancing and such high heels.....Oh but the pain was worth it!

What can be said about the food...it was divine and plenty for everyone, so much food....so little time!

Sunday morning and yet more food... enough already! It was now time to enjoy yet more interesting activities and the best of all, Pampering! There was the usual smorgasbord of hand and foot massage, manicures, pedicures, reiki and hair cuts. The perfect way to finish off a fabulous weekend.



So all in all the weekend was a success. We received lots of feedback which on the whole was very positive and complimentary. A lot of hard work went into the planning and organisation of the weekend and we appreciate the acknowledgement we received from the membership. We look forward to seeing you in the upcoming weekend in November.



# Mother's 60th Anniversary at the Hyatt

---

## Some of your wonderful feedback.....

"I would just like to say thank you for the privilege of attending this weekend. I had a fantastic time and feel very relaxed from the break. I also learnt about some new resources available and met some lovely people. You have all done an amazing job catering to such a large gathering".

"Firstly I would like to congratulate you on your hard work, empathy and compassion for all us Mums, Dads and siblings living with the day to day struggles of having a child with special needs. I commend you with my heart and soul and you cannot appreciate the amazing feeling we all get knowing there are wonderful people such as yourselves out there caring for us all".

"The guest speakers were excellent and informative, the yoga class was fantastic and the "why you click with some people" afternoon activity was brilliant. Some of our members were lucky enough to have their names "pulled out of the hat" for pampering, which they loved. The accommodation was fantastic and the food delicious. It was a real treat not to have to shop, cook, clean etc and have everything done for us! "

"I would like to take this time to thank you all personally for making such an amazing Mother's retreat possible! This was the first retreat I have been on, and I was soooooo overwhelmed by all the hard work that you all put into it. I felt very fortunate to be able to attend and it was above and over my expectations".





# Kalparrin Events

## Siblings School Holiday Programs April/May



On April 30, forty six young Kalparrin members enjoyed a day at Point Walter Recreation Centre taking part in climbing, flying fox and archery. We were very spoilt with the weather and it was an enjoyable day all round.

On the 2 and 3 May we treated our young members to a day out at the zoo. Kalparrin welcomed siblings from 7 to 15 years of age to

enjoy a day or two of strolling through a variety of the animal enclosures and finishing off the day with art and music sessions that were helped along by visits from Arty Umbrellas and Junkadelic. It was great to see so many budding artists among the children attending. - Cecelia Donovan, Events Coordinator.



## July

During the July Siblings Program we also discovered some amazing circus skilled youngsters amongst our sibling members! We held two siblings' days for 6 to 12 year olds and 9 to 16 year olds. On the 12<sup>th</sup> July, forty siblings enjoyed a wonderful winter's day performing outside in the park with samba style music, followed by a Circus Quirkus workshop.

Unfortunately the weather was not so kind on 16<sup>th</sup> July. It was a stormy, blustery day and so all activities had to be taken indoors. We had a fantastic group of kids join us for the days all enjoyed the team improvisations along with the circus workshop.

Considering the conditions, a highlight of the day was the hot chocolate and cookies for afternoon tea.

A big thank you goes out to all the parents that transported their children to our events. Just watching their happy faces and their interaction with other like-minded children is a real treat for us all. Many friendships are born from our siblings program and we hope they will continue when we see you next time! - Cecilia Donovan, Events Coordinator.



# Kalparrin Events

---

## Bruce Sullivan Dads Dinner - May

Recently I was fortunate enough to attend the Bruce Sullivan lecture. Lecture is probably the wrong word, this event was an “experience”.

Bruce is a relationship expert and has worked with individuals, families and communities providing education and opportunities for personal improvement. He took us all on a journey using his lived experience and knowledge. His outlook on life is simple and heart rendering.

Bruce spoke about being educated by his daughter (who has a disability) and the difference she has made to his life by learning to accept what one has and making the most of it Bruce uses a lot of humour which is effective, most of it aimed at himself, his term

“cranky pants” will live with me forever, I can still see them everywhere I go. He told a poignant story about children with many toys which was thought provoking sad, funny and mind changing.

I have been to see motivational speakers before and have come away with a few ideas. I wish I could remember everything that Bruce said as he is the best I have heard. I gained insight into a new way of describing myself and avoiding the mine field of emotions and feelings by looking at things a little differently. *“May you always remember that waking up is a really good start” Bruce Sullivan*  
- Shaun Murphy



---

## Couples Retreat - August

Recently I was fortunate enough to attend the Bruce Sullivan lecture. Lecture is probably the wrong word, this event was an “experience”.

Bruce is a relationship expert and has worked with individuals, families and communities providing education and opportunities for personal improvement. He took us all on a journey using his lived experience and knowledge. His outlook on life is simple and heart rendering.



Bruce spoke about being educated by his daughter (who has a disability) and the difference she has made to his life by learning to accept what one has and making the most of it Bruce uses a lot of humour which is effective, most of it aimed at himself, his term “cranky pants” will live with me forever, I can still see them everywhere I go. He told a poignant story about children with many toys which was thought provoking sad, funny and mind changing.



# Kalparrin Upcoming Events

---

## Sole Parents

**Applications are now open** for our **Sole Parents Day on 12<sup>th</sup> October** at the Nedlands Yacht Club.

Treat yourself to a day of reflection and pampering along with valuable information to fortify and support you with your daily life choices and experiences. Further details and an application form can be obtained via our website, Kalparrin email or phone the office on 9340 8094.



## Dads Day on the STS Leeuwin II



Another Day Event is in the planning. **Sunday 27<sup>th</sup> October, 11am to 2pm. Applications are now open.**

Come and enjoy a day of adventure on the replica sailing ship the "Leeuwin". Partake in sailing, navigating and climbing masts, whilst relaxing and socialising amongst friends and fellow Kalparrin dads. Further details and an application form can be obtained via our website, through Kalparrin email or by phoning the office on 9340 8094.

## Siblings School Holiday Program

Our next day program will be held at Point Walter on **8<sup>th</sup> October 2013.**

There are a range of activities offered on the day. Some of these Activities may include: Flying Fox, High Ropes, Climbing and Team Games, Archery etc. Come and join in the fun and meet other siblings. Applications will open September 10<sup>th</sup> 2013 for siblings aged 9 yrs to 16 yrs.



## Mothers' Weekend 8<sup>th</sup>—10<sup>th</sup> November



Our next Mother's weekend is being held at the beautiful El Caballo Blanco in Woorooloo. A weekend of pampering, fun, information, friendship and activities. Hope to see you there.

**Applications for this event will open September 16<sup>th</sup> and close October 4<sup>th</sup>. Any applications received either by email or post after this date will not be considered.**



# Kalparrin Upcoming Events

---

## Family Fun Day - Date to be Confirmed

Stay posted for details on this upcoming event

The Kalparrin website and e-news will post details about this event closer to the day. This is a day where all families and carers from all regions can come together in a safe and nurturing environment to enjoy a day of fun and recreation.



## Grandparents' Breakfast

We have a new event to now include our Grandparent carers and to acknowledge and celebrate the fantastic job they are doing. We are holding a breakfast at the Blue Water Grill in Applecross from **8am to 10am on the 19<sup>th</sup> October**. Information will be posted on our website, sent via post and e-news. We encourage all members to pass on this invitation to their Grandparent carers to encourage them to apply for this event.



*Please note applications are not a confirmation of your attendance. Kalparrin will process all applications for all events and confirm your place and registration via email or post. All applications need to be signed and completed in full.*

## Speaking out about Disability

Kalparrin was one of nine organizations chosen to take part in the research project called Speaking Out About Disability Consultation with Children in Western Australia. The Commissioner for Children and Young People this year is seeking the views, concerns and hope for children and young people with disability and their families.

The consultation process involves asking children aged 6 to 18 years, with a disability, a series of 9 questions. Our consultation process was to hold events and allow the children to feel relaxed in an environment where views and opinions could be expressed freely. Events have been Lego Fun, Secret Girls Stuff, Secret Boys Stuff and Visionary – drawing and painting your visions.

We developed our events to attract different ages and levels of interests. All have been thoroughly enjoyable. A huge thank you to K Kate Clark, Eileen MacClaughlin and Candy Goldsmith for their contribution. Thank you

also goes to all of those who have participated in the initiative, it has been an absolute pleasure to work with you all.

We have collated all the responses into a report that has been provided directly to the Commissioner Michelle Scott. The report will also be made available to many government and non-government agencies whose work impacts and supports children and young people with a disability. - Anita Peiris, Program Manager.





# Members Matters

At Kalparrin our members really matter so we have introduced a new page. If you have any significant event you would like to share like births, marriages and graduations, please send your story and a photo to [kalparrinwa@health.wa.gov.au](mailto:kalparrinwa@health.wa.gov.au) for publishing.

## Happy Birthday Shakira

Shakira Donovan celebrated her 18<sup>th</sup> Birthday on the 16<sup>th</sup> August 2013. Shakira was born with a complex congenital heart condition. She has had to face many struggles in her life including a secondary debilitating medical condition resulting from her heart surgeries. The impact on Shakira's life and ours as parents from this secondary complication has been vast, however as each day passes we appreciate the lessons and blessings that we have had bestowed upon us from having Shakira in our life. Congratulations on turning 18!



## In Memoriam

It is with great sadness that we acknowledge the passing of one of our early members Kaylene Coyle. Sadly, Kaylene lost her battle with cancer on the 28<sup>th</sup> June 2013 at age 55. She leaves behind her husband Gino, daughters KelliSue and Narkia and son Channon, and her grandchildren Imogen and Tyler.

Kaylene also leaves behind many memories with those who knew her and shared many good times with her. At her funeral, guests were asked to wear her favourite colour, purple. It was a sedate farewell, to a lively and colourful character, whose life touched the lives of many.



# Kalparrin Calendar of Events

---

## September 2013

- 12<sup>th</sup> Parents Pizza night on level 7 PMH Hospital at 7pm  
26<sup>th</sup> Kalparrin Coffee & Chat—Guest speaker from Independent Living Centre

## October 2013

- 8<sup>th</sup> Siblings day program—Point Walter Bicton  
12<sup>th</sup> Sole Parents Day—Nedlands yacht Club  
16<sup>th</sup> Carers Morning Tea—As part of Carers Week we will be hosting morning tea at the main entrance to PMH from 10am—10.30am  
19<sup>th</sup> Grandparents breakfast—Blue Water Grill Applecross  
27<sup>th</sup> Caring Blokes event—A day sail on the Leeuwin II

## November 2013

- 8<sup>th</sup>—10<sup>th</sup> Mothers Respite Weekend—El Caballo Blanco

## WASF UPCOMING EVENTS

### September 2013

- 16<sup>th</sup> 10.00am Coffee and Chat, Ellenbrook Christian Centre  
23<sup>rd</sup> 9.30am Coffee and Chat, Dome Café, Bunbury  
28<sup>th</sup> 10am-2.30pm SGS Social Group, Ellenbrook Christian Centre

WA Special Families and Kalparrin acknowledge and thank Telethon and Developmental Disability Council for their support

WA Special Families is an online Facebook community for families and carers of children with special needs. It is a place for families to communicate, share ideas and chat about life in a special needs family. To become a member, search Facebook for WA Special Families and request to join.



# Introducing the PMH LINC Coordinator

---

## LINC Program cares for carers

The APACHE Energy LINC Program (Liaising, Informing and Networking for Carers) was created in 2010 to support carers who provide unpaid care to a child with an ongoing disability or chronic illness, who are also receiving services at PMH. The free, hospital-based program ensures carers receive high quality support, information and practical assistance to make their experience at PMH as streamlined and enjoyable as possible.

The program strives to help carers in their role by:

- ◇ providing information about respite and support services for carers
- ◇ assisting with access to community based carer support services
- ◇ advocating on behalf of carers and their families
- ◇ providing information about seminars, workshops, social activities and special events of interest to carers
- ◇ assisting families to source counselling, recreational services and other 'time-out' opportunities external to the hospital.

Eileen Garside is enjoying her new position as the LINC Coordinator, “I love my role as LINC Coordinator as it allows me to meet extraordinary carers and their families and assist them in finding support services in the community to help them with their day to day lives.” She said that helping carers manage their child’s hospital stay and treatment is a rewarding experience and that having a non-medical support system at the hospital was important. Eileen is looking forward to new initiatives within LINC, including the creation of a LINC Plus Coordinator role for regional areas.

An important objective of the LINC Program is to provide education and increase staff awareness regarding community services available to children with complex needs, and to be aware of carer issues.

On Monday 29<sup>th</sup> July, the LINC Program held a free information workshop for carers to network with other family carers and representatives from Carers WA and Kalparrin.

The next free information workshop will be held in October. For more information, please email Eileen Garside at [linc.coordinator@health.wa.gov.au](mailto:linc.coordinator@health.wa.gov.au)



# Member's Story

## Jasmin's Journey

---

Seventeen years ago, I came to Australia from Switzerland, four years later Jasmin was born. Jasmin is a sister to our 20 year old son Roger. I had a fairly normal pregnancy and went to term with Jasmin. Two days after Jasmin was born, she was transferred to Princess Margaret Hospital due to respiratory problems associated with an infection. My daughter had been taken away. I had no idea what was going on or what was going to happen. Is everything going to be ok? Is this just routine?

I can still remember my first night without her, I couldn't have her next to me. I tried to calm myself down by believing that everything was going to be fine. It felt like an eternity until I was able to see her again the next day.

After a few days of Jasmin being ill, we had a meeting with the doctor. He told us that Jasmin was diagnosed with 18p- Syndrome, which was the cause of some early seizures. It was a big shock for us because there had been no indication whatsoever of any problems during my pregnancy. In simple terms, 18p- Syndrome is a chromosome abnormality in which one piece, from the short arm of chromosome 18, is missing.

I decided to start to do my own research and found some good information on the internet - The Chromosome 18 Registry & Research Society in San Antonio Texas, USA. Roger, helped too, he helped me join the "18p Yahoo Group". This support group was very helpful. It still is. I even uncovered some information from them that was helpful to Jasmin's doctors. My Local Area Coordinator has also been a support and has done a lot to help us. Whilst the internet was a great source of information about the Syndrome, I did get to the stage where I had to stop using it.

Having 18p- Syndrome has meant that Jasmin had episodes of being unresponsiveness or having "seizures". When she was three years and nine months she began to have growth hormones, these helped stop the "seizures" and although she still occasionally has one, they are infrequent. Other treatment included occupational therapy, physiotherapy and speech therapy at Andrea Way.

At the age of three Jasmin was still non-verbal and so we decided to learn Makaton. A year later, when Jasmin was four years old, she began at Carson Street Pre-Primary Special School. She was picked up by bus in the morning from home and returned in the afternoon. I can still see her, in my mind, leaving in the mornings. At five, as well as continuing at Carson Street Pre-Primary she went to kindergarten at the Language Development Centre. Slowly, but surely she started to say a few words! A few words soon became many words.

The other kids in her class were great. However, when Jasmin was in Year 3, we noticed that there was a significant "gap" between her skills and her peers. She was, for instance, still struggling to count to 10, while her friends were doing things like the times tables. I decided to consult with the Education Support Centre and within a few weeks she was in a new school, again.

Jasmin is now 13 years old and is in year 8 at high school. She has been at the same school now since that last change. The school is great, they teach the children more "life skills" such as cooking, counting money and catching public transport. They also have their own speech therapist.

She has come along way with the help of the school. Today her English and mathematics skills are probably the level of a five year old. I also help out where I can and sit on the School Council. Jasmin was, and still is, very easy going. She hardly has any tantrums and I could not wish for a better child.

One of the physical problems Jasmin has to contend with is that her body doesn't produce enough hormones, this is a condition called panhypopituitarism. As a result, her appearance is probably like that of a 7 year old. In humans, there is a particular bone our right hand that is measured to help indicate the 'bone age' of a person. Jasmin's bone age is 8! This means she needs daily growth hormones, along with cortisone and thyroid medication.



# Member's Story

---

The growth hormones are administered by injection. I still well remember the first day I had to give my daughter her first needle of growth hormones. It was quite overwhelming. I was so nervous. I was hiding the syringe and then quickly pulled it out, used it to inject her and then withdrew it as quickly as I could.

Amazingly she didn't recognise what was happening. After a week, I knew I could not hide it anymore. She had "wised" up". Now, it's as normal as brushing her teeth and we no longer use a syringe. We use a Genotropin Pen, which makes it so much easier.

I now look forward to the next step in the process, which I hope will be Jasmin administering the growth hormone herself. This would help her to live a more independent life, as this year I would really like to see her to participate in the school camps. I have worked hard to help her develop as much independence as possible. She can now shower without assistance, groom herself and can even prepare her own breakfast - no problem! Jasmin goes horse riding every Saturday, likes swimming and collects "Hot Wheels" toy cars. She is also amazing as she knows almost all the makes of cars she sees on the road.

I learn more from mums than any other people. We started a morning tea group at Jasmin's School. I came up with the name for the group, "DID YOU KNOW!". I like to help other families through the experience and knowledge gathered from my caring for Jasmin for the last 13 years. There is so much support here in Western Australia, for families with a disabled child. I believe it is my destiny to help my family, especially Jasmin, to become independent and to have a secure future.

- Monika Steiner



# Member's Story

## Caroline Runs for our Cause

A little bit about my journey.... 3 weeks ago I decided to sign myself up and create a team in the Karratha City to Surf (the first time ever held in Karratha and what an amazing event!) to fundraise for WA Special Families. At the time of signing up, I couldn't run 100 m but was more determined than ever to run the distance, as my little guy with cerebral palsy has been making amazing progress, and my motto was, if Jaiden can do what he has been doing, I could run the 12 kms!

I spoke to a friend John (pictured with me at the right) and he took on the challenge of helping me! Within 3 weeks I was running 5kms non stop.

Sunday morning of the big race came and I was absolutely pumped!

The run went really well, I got to the 11 km mark and instantly got goose bumps and tears starting rolling down my face. When I came around the corner, my team of amazing friends, who had finished well ahead of me, were waiting at the 11.5 km mark to help me run the last 500 m to finish the race!

By this point I was crying uncontrollably! I couldn't believe I had finished the 12kms without stopping and came in under my goal time and I wasn't even last! Once I stopped I looked over and could see my two kids cheering me on. My little boy Jaiden, for the next 2 days, kept telling me how proud he was of me! It just proves that if you put your mind to something you can actually do it!

I haven't done anything for myself since having a special needs child and I now believe I need to do this. I now realise that taking a little bit of time out for me is making me a better mother to my kids and I would never have believed that before now! I really encourage all of you to get involved in a Fun Run, as you feel so amazing and accomplished once done! So far I have raised almost \$1700 for Kalparrin!

Caroline Taylor



## Editor's Update - Alexey's story

In the last Kalparrin Cares we ran a story on Alexey. This courageous little boy suffered from a massive hemorrhagic stroke when he was only a month old. His mum Anna shared her story with us and would like to show you a picture of her 'miracle boy' Alexey.

As you can see he is a beautiful boy with a cheeky grin and quite the artist! Thank you Anna for sharing your story and showing us that Alexey, despite his challenges, is doing really well.





The Kalparrin Centre, Level 4 Hay Street Building,  
Princess Margaret Hospital, Subiaco, Western Australia 6008  
Phone: (08) 9340 8094 Free call: 1800 066 413  
Fax: (08) 9380 6114 kalparrinwa@health.wa.gov.au  
www.kalparrin.org.au  
**ABN 20 440 047 551**



## Membership Application

(membership is free for families of children with special needs)

Name: \_\_\_\_\_

Address: \_\_\_\_\_

Suburb: \_\_\_\_\_ State: \_\_\_\_\_ Postcode: \_\_\_\_\_

Phone: \_\_\_\_\_ Mobile: \_\_\_\_\_ Email: \_\_\_\_\_

Organization (if applicable): \_\_\_\_\_ Job title: \_\_\_\_\_

Child 1: \_\_\_\_\_ Date of Birth: \_\_\_\_\_ Sex: \_\_\_\_\_

Primary diagnosis/special need: \_\_\_\_\_

Child 2: \_\_\_\_\_ Date of Birth: \_\_\_\_\_ Sex: \_\_\_\_\_

Primary diagnosis/special need: \_\_\_\_\_

**Please send me email news bulletin**  Yes  No

**I would like to receive Kalparrin Cares Newsletter as**  E-Copy  Hard Copy

### Kalparrin Privacy Statement

Kalparrin respects the privacy of its members. Please read our Privacy Statement. See *Kalparrin website*.

### Kalparrin Membership Charter

I have read and agree to abide by the Kalparrin Membership Charter. See *page 5*.

**Parent Link**  Yes  No  Not Applicable

I'm happy to be contacted by Kalparrin with a view to being linked with another parent in a similar situation.

## PROFESSIONAL / ORGANISATIONAL MEMBERSHIP PAYMENT TAX INVOICE

(health professionals or other service providers)

Professional Membership \$38.50 (Incl. GST)  Organisational Membership \$38.50 (Incl. GST)  
Please find my cheque / money order (made out to Parents of Children with Special Needs)  
**OR** Please find my credit card details below:

Cheque/Money Order  Visa  MasterCard

Card Number: \_\_\_\_\_/\_\_\_\_\_/\_\_\_\_\_/\_\_\_\_\_

Expiry Date: \_\_\_\_/\_\_\_\_

CVV: \_\_\_\_ (Your Customer Verification Value (CVV) is a 3-digit security code on the back of your credit card. It appears on the signature panel after and to the right of your card number.)

Name on Card: \_\_\_\_\_ Signature: \_\_\_\_\_



POSTAGE  
PAID  
AUSTRALIA

SURFACE  
MAIL

Parents of Children with Special Needs  
ABN 20 440 047 551  
**KALPARRIN CENTRE**  
Level 4, Hay Street Building  
Princess Margaret Hospital, Subiaco  
GPO Box D184, Perth WA 6001  
Telephone: (08) 9340 8094  
Freecall: 1800 066 413  
Fax: (08) 9380 6114  
E-Mail: kalparrinwa@health.wa.gov.au  
www.kalparrin.org.au

**Open Monday to Friday  
8.30am—4.00pm**

## Parents of Children with Special Needs Inc.

ABN 20 440 047 551

### Donation Form

Parents of Children with Special Needs Inc. (operating as Kalparrin) is a not-for-profit organisation recognised by the Australian Taxation Office as a Deductible Gift Recipient. All donations of \$2.00 or more are tax deductible. Your donation will help us provide our services supporting families of children with special needs.

I wish to donate:  \$5.00  \$10.00  \$20.00  \$50.00  Other Amount - \$ \_\_\_\_\_

Name: \_\_\_\_\_ Address: \_\_\_\_\_

Post Code: \_\_\_\_\_ Phone: \_\_\_\_\_

Cheque/Money Order       Visa Card       MasterCard   
*Please make cheques payable to Parents of Children with Special Needs*

Card Number: \_\_\_\_\_ / \_\_\_\_\_ / \_\_\_\_\_ / \_\_\_\_\_ Exp: \_\_\_\_ / \_\_\_\_

CVV: \_\_\_\_\_ (Your Customer Verification Value (CVV) is a 3-digit security code on the back of your credit card. It appears on the signature panel after and to the right of your card number.)

Name on Card: \_\_\_\_\_ Signature: \_\_\_\_\_

**Thank you for supporting Kalparrin!**

