

Welcome to 2019 from Self Help Queensland

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### Support 4 Support Groups!

Self Help Queensland supports people to find their own solutions to improve wellbeing. We connect people to support groups across a broad range of health issues, assist people to start new groups and work with support groups to build their capacity. SHQ promotes community awareness of the benefits of self help groups for the wellbeing of individuals coping with adverse life circumstances.

[Donate now to support our work](#)

## Beginning anew 2019 ...

- [Calendar Chaos](#)
- [Q and A what we've been asked about](#)
- [Let's get started 2019](#)
- [New Year's Resolutions, to resolve or not to resolve](#)
- [Fundraising - our tips to start the year](#)
- [Genetic Matters - 3 parent babies](#)

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## Calendar Chaos

There are calendars in the world dating from 8000 BC, so humans have a long tradition of planning when we begin the New Year. Back then, they used the sun as their guide. Now we have the internet, maybe their days were less chaotic! How many calendars do you have - one on your phone, on your wall and a few floating around on desks? Appointment cards scattered about? Maybe the first new year's resolution is to try to organise your calendar.

We've scheduled our management meetings for the year, we've set a break for Easter

As part of our planning, we have decided that Self Help Queensland will be open on Thursdays until 7pm. This is to support all of our groups who are volunteer based. Yes, you can connect after your day job, not just in the five spare minutes you never have. We will be open for meetings, training, telephone, skype and more! We are starting our planning now, so contact us with your ideas or make an appointment with us at Sunnybank.

In our next newsletter, to celebrate all the support groups who work with rare diseases, we will be featuring groups who support rare. February 28th is Rare Disease Day. If this is your group – please send Selina a paragraph and/or photo before February 21<sup>st</sup>. We want to showcase you. (Note: a rare disease is one that affects less than 1 in 2000 people.)

Is there anything else you'd like to see on our calendar in 2019? If you have dates to share via our newsletter or facebook, please let us know.

Best wishes from the Self Help team,  
Selina, Melody, Joe, Kathy, Chris, Lil and Justin.

*"Never doubt that a small group of thoughtful, committed citizens can change the world: indeed, it is the only thing that ever has."* Margaret Mead

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## **New beginnings!**

We welcome Justin to our Management Committee, pictured here with his new grandchild.

## **Q & A at Self Help Queensland**

### **Question**

In November, I was asked for an addiction support group or service in a small town in Queensland.

### **Answer**

that town, an hour away.

### More questions

By chance one morning three months later, I found an organisation doing outreach support once a week, and I can't reconnect with our anonymous caller. I ask myself if I can't find anything with all the directories, computing and regional knowledge I have, how do people find support at the beginning of their journey? Particularly if they are secret keeping? I would welcome your insights.

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## Let's get started: 2019

### Did you know?

Self Help Queensland started in 1983. The initial focus of the organisation was that mothers needed support in the Logan area when they had a new baby, to overcome both geographic and emotional isolation. In 1984, it ran its first Leader's Workshop. Topics in the book include first aid, relating to your health advisor, problem solving and understanding medicines.

### Even though you're nervous, walk in the door, push the send button, join a group!

Meeting other people who are going through something the same as you can provide a burst of relief, a wealth of new information or a way to be well. Since we're all about groups, naturally we would say this. However, someone told us recently that before they joined their group, they didn't believe it was possible to recover, now they do. What a powerful message.

### Fresh approach to low back pain

Finding health information on the internet can be tricky. [Medicinewise](#) has great digital information for health consumers, including their new guide to low back pain.

### New guidelines and systems for the Patient Travel Subsidy Scheme (PTSS)

If you have to travel more than 50km to see a recommended specialist, you may be eligible for the [PTSS](#). New guidelines and an on-line application process are now available.

### And one hundred years ago...

*The Queenslander, 18 January 1919 "The Magic of Self-Help" O Hashnu Hara*

*"Two weeks ago that hedge was leafless and every vestige of green had been devoured*

*surely you can do the same? If success has been denied to you, as you understand success, and all your efforts have been eaten up by ill-luck, put up a new fight, clothe your ambitions with fresh leafage, and try again."*

(yes, really, we didn't make this up)

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## Do you have a new year's resolution?

We've all done it before. Beginning the New Year with a goal we set for ourselves and are confident we will achieve. Gradually lost focus and motivation, ended up back where we started but with increased feelings of guilt and hopelessness. This is a common problem; researchers found that 80% of resolutions are off track or abandoned by the beginning week of February. The challenge for all of us is to modify behaviour long term, rather than just for a few short weeks.

### What doesn't work...

Goals that are too vague. A goal such as 'eat healthier' is not easy to measure. How will you eat healthier? Replace your crackers for carrots? Give up coffee?

Goals that are unrealistic. If you've been a total couch potato, working out twice a day is unlikely to happen straight away. Start small, such as some gentle exercise once a week and then increasing in intensity and frequency each month.

Having too many goals is also a large factor in the inability to make change. Often people create a long list of what they want to achieve. Motivation and attention become too split and it produces an unsustainable behaviour change.

### What does work...

Although it may seem obvious, you are more likely to continue with a goal if the motivation comes from within you, rather than externally. For example, you may feel pressured by society to be fit and athletic. However, if your dream is to run, walk, swim or wheel a kilometre along the beach walk at sunrise before your next big birthday, you will push yourself.

Another tip is to create strategies and integrate them into your daily routine. For example, you may want to relax more. Every morning you may go and sit in the same place and have a cup of tea. Try meditating for five minutes after that. Or develop a practical strategy, such as leaving your mobile phone in another room, not beside your bed.

friends about your goal; having an encouraging support network can help, although make sure you also share how you need them to help you.

A useful way to maintain motivation is to celebrate small wins. Reward yourself with something simple that reflects your goal eg. A trip to the beach, listen to an old favourite song.

Setting up sustainable, small behaviour changes takes time. We can't expect ourselves to be perfect all the time and a resolution shouldn't be one more load of feelings of guilt and shame. People who accept they messed up and get back on track are more likely to succeed than those who spend days dwelling on their mistake. The key message is to be kind to yourself. No journey is smooth, and it will always contain ups and downs. The important thing is that you recognise the need to begin the journey in the first place and take a single step forward.

## Maybe 2019 is the year to give up resolutions!

[This blog](#) suggests that PTSD and new year's resolutions really don't mix.

And for everyone who has started the year rushing around, here's a [song](#) for you!

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## Fundraising - our tips to start the year

### Fundraising #1

Money is a means to an end. Do you need actual cash or would something else make a larger difference to your resources. For example, what if an expensive medication was listed on the PBS and all of your group members had an extra \$50 per month? What if you approached the UQ pro bono law school and got six young law students on your cause? What if your website had a Q&A so you weren't answering basic questions on the phone? Thinking about money comes after thinking about strategy, don't narrow down too quickly. Begin with what you want to do and then think how you could gather in the resources to get it done.

### Fundraising #2

Does your group have a signature event? Is it in tune with what you do? The purpose of an event is three dimensional: it helps your people to connect or learn, it strengthens your place in the community and it is financially successful.

Whether you are planning a new event or your regular one, we suggest that you make sure you've figured out how to measure your success across the three

Sometimes it can be easier to work backwards. Figure out what the success looks like and then try to make it happen. Is the balance across the three dimensions what you want? If you focus on one dimension too quickly, the other two may be at risk. Maybe it will take more than one event attempt to make your targets but start with the end in sight.

### **Fundraising #3**

Don't forget that not-for-profits with an ABN are often eligible to apply for grants that are targeted at small business or schools. For example, the Maker grant is now open. This provides \$5000-\$20000 worth of funding for young people to engage with science and technology. If you work with children with special needs, this is an opportunity to set up a STEM project that meets their needs – the next robotic arm? A new app for managing their condition?

<https://www.business.gov.au/assistance/inspiring-australia-science-engagement/maker-projects-stream-b>

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## **Genetic Matters: Babies with 3 parents**

by Professor Kim Summers PhD FRSB

The UK has recently granted approval for doctors to create babies with three parents. This process is used to overcome the problems caused by genetic mutations of the special small circular DNA molecule that exists, independent of the main DNA, in small organelles called mitochondria (singular: mitochondrion). Mitochondria are responsible for energy production in the cell, using oxygen delivered by the bloodstream to break down the nutrients in food and release energy in a form that can be transferred around the cell.

Mitochondria are said to be semi-autonomous, that is they have some of the machinery to perform their functions without involving other cellular components. They can make some proteins and they have their own DNA molecule which contains the information for a small number of the proteins they need. But the majority of the structure of the mitochondrion comes from the main cellular DNA and the proteins are synthesised outside the mitochondrion and imported in. In fact, mitochondria only make 13 of the many hundreds to thousands of proteins that are needed for their function. But if something goes wrong with the small circular mitochondrial DNA, it can result in a devastating disease that affects the muscles, eyes, brain and other organs. This new approval provides a way for families with a mitochondrial condition to avoid passing it on to children.

the father rarely contributes any mitochondria to the new baby. So both sons and daughters inherit their mitochondria from their mother. As the fertilised egg divides and begins to develop the different organs and tissues, the mitochondria within the cells also divide. Each cell has many mitochondria, depending on its energy requirement, and each mitochondrion has many copies of the small circular mitochondrial DNA molecule.

Each mitochondrion can have a mix of normal and abnormal DNA. And each tissue can have a mix of mitochondria with high and low loads of abnormal DNA. As long as the majority of the mitochondrial DNA molecules are normal, a person is unlikely to show any symptoms of mitochondrial abnormality. But if the load of abnormal DNA is high in a tissue with high energy demand then symptoms are likely to develop. So the severity of the symptoms depends on the proportion of abnormal mitochondrial DNA and the tissue type.

Because the proportion of abnormal mitochondrial DNA molecules is determined in part by the proportion in the mitochondria of the egg, a mother who has a small number of abnormal mitochondria and no symptoms can have a child with a much higher proportion and therefore the possibility of a severe condition. This is where the newly approved approach can be helpful. With advances in IVF, doctors can create a fertilised egg from the two parents. They then remove the nucleus (which contains all the cellular DNA) and use it to replace the nucleus of the egg of another woman who does not have a mitochondrial disease. The “three parent egg” can then be implanted back into the mother who will give birth to a baby who has her and her partner’s DNA in the nucleus but the other woman’s DNA in the mitochondria.

The technique has been possible for a long time; it is essentially the same way that Dolly the sheep was created more than 20 years ago. But using it in humans, and working through the ethical and biological issues of creating babies with three parents, has taken many years. The first baby produced this way was born in Mexico last year. Now doctors in the UK are preparing to use the technique for two women who have a genetic mutation for MERRF syndrome (myoclonic epilepsy with ragged red fibres), a mitochondrial condition that can result in movement problems, seizures and heart disease. Using the mitochondria from another woman will mean that their babies do not have the risk of this condition.

You might wonder how a mother with such a severe condition could support a pregnancy and then look after a baby. There is no information about how severely affected are the women chosen for the first procedures. Presumably this reflects the irony of mitochondrial conditions: the mother may have only mild symptoms because the load of abnormal DNA is quite low. But if the egg ends up with a much



the risk of a severe disease. In addition, mitochondrial conditions tend to worsen with age, so a young mother may have a low level of symptoms.

Now this is approved in the UK, other countries will be watching eagerly to see how the first women progress with their pregnancies and how the babies develop. The technique has also been suggested to increase the success of IVF in older mothers, who may have accumulated abnormalities of their mitochondria that contribute to low success rates. But there are potential problems that will only be known after many procedures have been reported, including genetic incompatibility between the nucleus and the mitochondria that come from different people and the possibility that the donor might have a low level of mitochondrial abnormalities.

This development shows how a combination of scientific knowledge, of mitochondria (which have been studied for more than 60 years), of in vitro fertilisation techniques (which have now been in use for 40 years), of nuclear transfer (for example producing Dolly more than 20 years ago) and of inheritance patterns (first studied by Mendel more than 150 years ago), can lead to a clinical development that helps families at risk for devastating diseases.



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We are open Tuesday, Wednesday, Friday from 9am to 4:30pm, Thursdays until 7pm

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