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Message from the Trustees

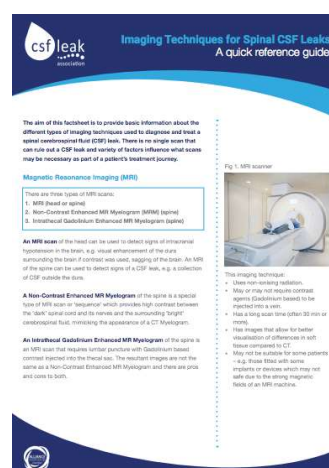
Hello, <<First Name>>.

We bid you a warm welcome to the summer edition of Leaker Life.

This newsletter focuses very much on the leaker community, with the spotlight cast on clinician, trustee and leaker alike. We also turn to you to offer our ongoing thanks, and also to ask for help – we are in need of volunteers and trustees here at the CSF Leak Association HQ and welcome applicants from UK based leakers and non leakers to come on board – however much or little you can offer; we need you!

Included in the newsletter are details of a recent publication, as well as an update on the hugely popular and successful Kilt Ride, Scotland’s largest motorcycle fundraiser, which entered its third year this May!

Last, but by no means least and just when you thought you’d left GDPR behind... We've been working hard for many months to be compliant with the new regulations. Our application forms were



Imaging Techniques for Spinal CSF Leaks - a quick reference guide

Earlier this year we released a guide to imaging techniques for Spinal CSF Leaks. The aim of the factsheet to provide basic information about the different types of imaging techniques used to diagnose and treat spinal cerebrospinal fluid leaks. There is no single scan that can rule out a CSF leak and a variety of factors influence which scans may be necessary as part of a patient's treatment journey. You can find the guide on our website, or by clicking [here](#)

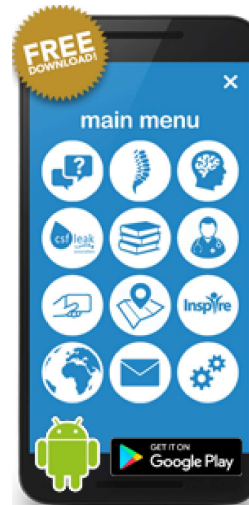
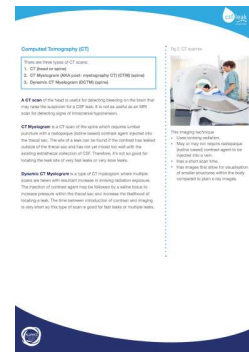
updated over a year ago, and members can request a copy of any data we hold relating to them at any time by contacting us at office@csfleak.info. In addition, you can unsubscribe from any of our email communications by using the unsubscribe button. If you have any queries or questions, please do get in touch.

As always, thank you for reading and for your ongoing support.

With best wishes

David, Polly, Debs, Deborah, Tamsin, Clare and Pete

The Team of Trustees at the CSF Leak Association



If you've got an android mobile phone or tablet, why not download our brand new CSF Leaker Companion app?

[Find out more](#)





Head on over to our merchandise shop at www.csfleak.info/shop/ where you will find a fabulous selection of useful items and clothing. Each sale raises a small amount for the CSF Leak Association, and can help to spread awareness. Merchandise can be used for sporting activities or fundraising events, given as gifts, or even a treat to yourself! Wristbands and button badges can be given as wedding favours and mugs donated to clinicians. The options are endless!

We always love to hear from you if you have made a purchase and to see your goods in action. So please share via social media with a bit of an explanation about who we are and include the hashtags [#csfleak](#) [#uprightheadache](#) [#spinalcsfleak](#) [#wearbluetoo](#)

Please send over your 'mug shots' to us at newsletter@csfleak.info





Get involved.



We're looking for volunteers to assist us and help us raise awareness of CSF leaks

WE NEED YOU!

Here at the CSF Leak Association we are all working hard to propel the work of the Association forward, to raise awareness, to work closely with the Medical Advisory Committee to prepare and publish new educational resources and materials, to support the adoption of clear and consistent diagnostic and treatment pathways within the NHS and, ultimately, to encourage and facilitate research so that the condition can be better understood. We have grown rapidly, and as we forge ahead, our workload has inevitably and dramatically increased. As a result we desperately need your help! We are urgently looking for UK based volunteers and trustees to enable to continue to keep up the momentum of our hugely positive developments. Perhaps you know someone with a little time to spare on a regular basis searching for a purposeful and rewarding activity? You don't need to be a leaker to apply – friends, family members are all welcome. Please get in touch if you could help!

Please contact us at: volunteer@csfleak.info



We are delighted to take this opportunity to begin to introduce the members of the Medical Advisory Committee individually, with Dr James Walkden, Neurosurgeon at the Aberdeen Royal Infirmary, the first in the limelight.

"I am from Angus, Scotland and grew up in a small town called Kirriemuir, which is famous for Peter Pan author JM Barrie and AC DC singer Bon Scott. I studied at St Andrews University obtaining a Bachelor of Medical Science before switching to Manchester University to complete my medical degree which I achieved with Honours. I worked in Tauranga Hospital, New Zealand for 4 months prior to starting my junior doctor rotation at Salford Royal. I was successful in applying to the national Neurosurgery training programme and was matched to North West which meant a return to Salford as well as Royal Preston and Manchester Children's hospitals. I completed training in 2014 and moved to the Walton Centre in Liverpool for a year Fellowship in Neuro-oncology surgery. I was subsequently appointed as Consultant Neurosurgeon in Aberdeen in September 2015.

I have a 6 month old baby boy to entertain at the moment but my other hobbies are football, tennis and fishing. My interest in CSF leak as with most things started by chance having encountered some complex patients with CSF disorders during my time in Salford and Walton and some of my previous consultants there having an interest in ICP monitoring. There is still a huge amount we don't know about CSF disorders but a logical and stepwise approach to diagnosis and investigation is critical".



Dr James Walkden, Neurosurgeon, Aberdeen Royal Infirmary

A banner for Leak Week UK 2018. The banner is split into a dark blue top half and an orange bottom half. On the left, the text 'Leak Week UK' is in white, with '26 Feb - 4 March' below it. The year '2018' is prominently displayed in white, with a blue water drop icon containing a brain and spine illustration integrated into the '0'. Below the year, it says 'Raising awareness of cerebrospinal fluid leaks'. On the right, a list of topics is shown in white text: 'What is a leak?', 'Symptoms', 'Diagnosis', 'Treatment', 'Aftercare', and 'Living with a leak'. The 'csf leak association' logo is in the top right corner.

THANK YOU for participating in our Leak Week 2018 survey!

We received overwhelmingly positive feedback and also a number of helpful suggestions of how we might focus awareness weeks in the future. One point in particular that was raised a number of times was –

'To please include stories of real life leakers that include misdiagnosis / that

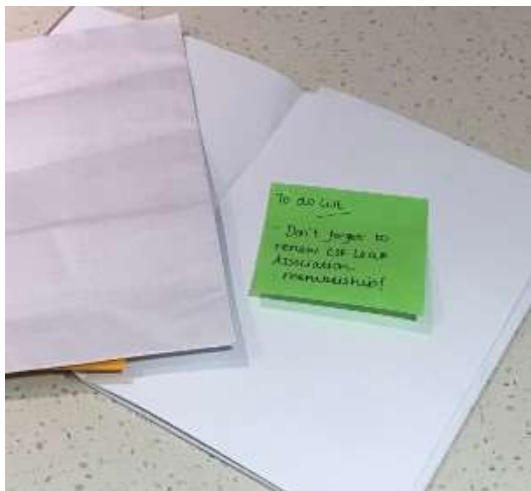
aren't purely positive / that include different types of leaks'.

Did you know that Leak Week resources can be accessed anytime via our website – both Leaker stories and videos – and would urge you to revisit them as we had purposely included a range of leak types, with varying outcomes. Many of the stories featured ongoing leaks or pending surgery, and the types of leaks included ranged from spontaneous to iatrogenic to trauma, cysts and bone spurs, as well as both spinal and cranial leaks.

You can find the Leaker Stories on our website: www.csfleak.info by following:

Living with a Leak >> Patient Experiences

As always, please get in touch if you have any thoughts or ideas for future awareness weeks, or if you would like to get involved!



Are you an existing member whose annual membership is about to expire? Perhaps you've been meaning to join up for a while but haven't managed to yet? Or maybe you know somebody that would appreciate a membership as a gift?

We rely solely on the generosity of our supporters, members and fundraisers to keep things ticking over at the CSF Leak Association, so please don't forget to join up or renew your membership to keep up to date with the latest news and developments, as well as benefiting from a free gift when you renew! To renew your membership, please click [here](#).

To read more about the benefits of becoming a member and to join us, please see our membership overview by clicking [here](#).



Name: John Brennan

Age: 49 (age 28 at the time of first injury, age 46 at the time of diagnosis)

Location: Newport, Rhode Island

Type of Leak: Cranial Leak



"My ordeal began in January 1997 with a routine sinus surgery. It would be July 2015 before it was discovered that a quarter-sized piece of the thin base of the skull above the sinuses had accidentally been removed.

At the time, I was a busy actor, writer, and photographer, and I would remain so until 2015. By then, I would be living and working in Newport, RI with my wife and three kids. I also worked nights for the security of a steady paycheck and for the health insurance benefits.

That schedule seemed to be taking a toll on my health. I lived with worsening pain. Also, I would get knocked unconscious about 2-3 times a year and I often had post-nasal drip that did not respond to medications. By August 2010 I had decided to switch to a day job for my health. During that transition, I had a series of mini strokes caused by my brain slipping through the hole. I lost math, including the ability to count above three. I struggled with my new job counting pills, but I managed with the help of the automatic pill counter and my customer service skills.

Then came THE DAY. July 18, 2013- the day after my 44th birthday. I arrived at work at 10am feeling great. At Noon, I began to get a headache. Within minutes, it was the worst migraine ever. I staggered into the shelves and collapsed. By 1pm, I was delirious. I woke up four days later. I had survived bacterial meningitis.

After I recovered, I continued to perform, work, spend time with family, and even ride my motorcycle regularly. Early in 2015, I got pneumonia twice. On the weekend of July 4th, we had a big party. I thought I had strained my neck, because I had a terrible headache. After four days of stabbing pain, I collapsed again. The diagnosis was a total shock for everybody- pneumonia and meningitis. Fortunately, this was a much milder strain.

Finally, they found the hole that had been hiding in my head since 1997. The scans showed that the bone had tried to heal, but the gap was too large, so the bone grew into spikes jutting into the brain. My left sinus cavity was filled with about an egg-sized lump of dead brain tissue. They pushed that back into my skull and sealed the hole using tissue and cartilage in my sinuses.

My deterioration had been gradual, but in those final years, it accelerated. The initial injury left me with a CSF leak that filled my lungs- my chronic post-nasal drip and eventual pneumonia. The intermittent pressure loss deprived my brain of a vital cushion, causing intense migraines and allowing for easy concussions. The brain was directly exposed to the air in my sinuses, allowing easy access for meningitis-causing organisms. Dancing and performing slapstick would cause my brain to slip past the bony spikes, causing mini-strokes. Putting it all back together added insult to injuries.

I awoke from surgery in unimaginable pain, but I forced myself to smile. The pain meant that I would recover, and that I would get to hug my family again. I live with new challenges now- neurological pain, loss of proprioception and balance, and memory loss. I have to work every day to remember even my own family. I can't drive and can't always walk safely. I still perform sometimes-though with restrictions. My youngest daughter, now in fifth grade, has been teaching me math and we play music for fun and therapy.

Most of my negative emotions fell through that hole- fear, sadness, anger, and stress. I am blessed to have a wonderful support group of family, friends, and community. I'm grateful for that. I don't remember yesterday and I can't worry

about tomorrow. I live in the moment. I'm glad it's a nice moment".



"Here is the CAT scan of my injury when it was discovered in 2015. The damage was done to my left side (on the right in this photo).

You can see a bone extending from the right eye socket to the nose with a small ridge on the top that is missing from the left eye.

Just beneath where that should be on the left eye, there are two bone spikes extending into the space. Over the years, the bone tried to repair itself, but the gap was too wide, so the bone grew into bony crystalline reaching into the tissue.

The gray areas are soft tissue. Above the eyes, of course, is brain tissue. The scan shows a mass of tissue that had prolapsed into the sinus cavity below. Those bone spikes were a double-edged sword, as they held the brain in place, but when it slipped, they tore into it as well.

You can see the clear spaces of the sinus below my right eye compared to the tissue-filled sinuses on my left".



"After my surgery to repair the leak, they drained my spinal fluid to keep pressure off of the repair site. My daughter Mackenzie took this selfie with the bag and posted it to her social media with no explanation. She is a funny young lady!

I am so grateful that I have the chance to watch my children grow! Mackenzie recently went to Missouri to present a research paper on the effects of memes on the 2016 US elections. She spent last week presenting a research paper in Havana, Cuba on the use of standard grammar rules in academia to marginalize English-speaking people of Caribbean dialects, and in August, she will begin a year of study in South Korea!"



"My surgery was scheduled for November 11, 2015. On Halloween, after giving out lots of candy, I saw a friend passing by with a friend of hers. We invited them in for some drinks and by evening end, the friend of a friend whom I had never met agreed to begin shaving my head. I had decided to leave a Mohawk for the evening, and this kind young lady shaved a stranger's head on Halloween.

On November 1, we celebrated the Day of the Dead at my parent's house with a Finnegan's Wake in my honor. We were confident about the outcome, but we wanted to cement one last joyful memory with the family, just in case. We made our best attempt at creating Liberty Spikes from my Mohawk. The second picture shows (left to right) my son Mike blow drying my hair, held high in a spike by my daughter Mackenzie with help from my sister Dawn. My youngest daughter is not pictured, but she helped as well.

Afterwards, my mom shaved the final bit of hair (3rd photo) and we donated my long locks to a charity".



John, thank you for sharing your story, your positive outlook, and your fabulous pictures!

If you would like to share your Leaker story for inclusion in our newsletter, please get in touch via newsletter@csfleak.info



Raise awareness globally

If you're active on social media, why not check out our [Twitter feed](#) and [Facebook page](#)? We publish regular updates, news, articles and announcements about CSF leaks and related conditions. If you wish to post your own content on social media about CSF leaks, why not use the following **#hashtags** in order to maximise exposure and secure awareness across the globe?



#CSFleak #SpinalCSFleak #headache #IntracranialHypotension #LeakerLife #uprightheadache

A promotional graphic for the CSF Leak Association's Instagram page. It features a large Instagram logo in the center, with a mouse cursor pointing at it. The background is dark blue at the top and orange at the bottom. Text includes the CSF Leak Association logo, a call to action to follow on Instagram, and the website URL. A small note at the bottom states the charity number.

csf leak association

If you've not already found us on Instagram, why not visit our page & follow us today?

Follow us on Instagram

[instagram.com/csfleakassociation](https://www.instagram.com/csfleakassociation)

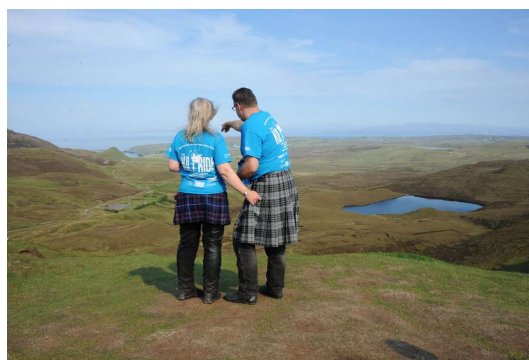
The CSF Leak Association is a Scottish Charitable Incorporated Organisation (Charity No. SC046319)

Did you know that during Leak Week we launched our Instagram account? Head over and follow us - and link your photos and images with the hashtags - which you can also follow on Instagram!

A banner with a blue background and colorful bunting at the top. The text 'Fundraise for us' is written in large white letters. Below it, a circular icon shows a hand holding a heart, with the text 'Support us through fundraising or a donation' next to it.

Fundraise for us

Support us through fundraising or a donation



[The Kilt Ride – raises over £1600 in its third year!](#)

Scotland's largest motorcycle fundraiser to support the CSF Leak Association took place between 26th-28th May and included a full day tour of the Isle of Skye.

Starting at the historic ground of Bannockburn, passing Stirling Castle, the riders followed the tight twisty roads along Loch Lubnaig. This road led them to

the magnificent and famous Glencoe Pass and on towards Fort William. From Fort William it was another great ride, stopping off to show respect at the Spean Commando Memorial, before enjoying the amazing ride on the A87 to the world famous Eilean Donan Castle. After brief stop for photo opportunities and rest, it was just a short ride on to The Isle of Skye. Kyleakin is just on the other side of the Skye bridge and was the perfect setting to call home for 2 nights.

Day two, involved a relaxed tour round the Island; taking in Skye's most breathtakingly stunning scenery, riding along smooth wide easy roads, as well as the more challenging, sheep dodging single track roads. It's the single tracks that take more concentration due to uneven cambers, gravel etc, but every meter was worth it. Returning back to base in Kyleakin, the bikers enjoyed a relaxed evening of food, drink, the charity auction and some light entertainment.

Day Three was open to participant's choice with two routes on offer. Route one was the reverse route of day one missing out Glencoe taking the B road from Spean to Dalwhinnie and onto the A9. The Route two option was a longer ride, looping up over the amazing Sheildaig and Torridon to Inverness then cutting down through the Cairngorms over the Lecht and Glenshee. Both routes ending at Perth Tesco and fragmenting as riders headed for home, after another hugely enjoyable and successful fundraising weekend.

As always, we wish to extend our heartfelt gratitude to Ray Michael (aka The Scotorian Biker) for his ongoing commitment to raising vital funds for the CSF Leak Association, and his dedication to raising awareness of the condition; and of course to the 70 wonderful bikers who took on the legendary Kilt Ride challenge!



A blue banner with a white background for the text. On the left, the word 'NEWS' is written in large, bold, white capital letters. To the right of the text is a white icon representing three stylized human figures. Below the icon, the text 'Latest news from the Board of Trustees' is written in a smaller, white font.

We are delighted to introduce our new article, in which we hope you will be able

to get to know the charity Trustees a little better, and to hear each of our own leaker stories.

Tamsin Trevarthen gets the ball rolling in this edition.

"I have suffered with headaches for most of my adult life but in January 2011 I began to get daily headaches which were quite unlike anything I had experienced before. Having relocated to Ireland six months previously, for a bigger job, the general consensus was that they were attributable to stress. But I was never convinced by this. I just knew something was wrong. As weeks turned into months I was assessed by two neurologists, one of whom told me "there was nothing special about me". Words that remain with me to this day and, in my view, should never be uttered by medical professional. I was prescribed a cocktail of drugs but nothing helped to alleviate my pain. Apart from lying down.

Ten months later, with no diagnosis, I reached a point where I was unable to work and my quality of life was minimal. I didn't know where to turn for answers and felt more isolated from family and friends than I had in my entire life. I couldn't tell anyone just how bad things had got. I tried many alternative therapies after feeling let down by the medical profession, the last of which was with a cranial osteopath. In our first meeting she laid her hands on my head and immediately commented that I had very little fluid around my brain. It felt very significant in my search for an answer.

That night I did my own research and read about CSF leaks, and for the first time my symptoms began to make sense. With that in mind I got an appointment with Dr Matharu at the NHNN shortly after and my suspicions were confirmed following ICP monitoring a few weeks later.

Two x caffeine infusions, four EB's (the last of which was a success) and one lumbar infusion study later and I was still struggling with low pressure headaches, and the recommended solution was surgery. I was admitted for a VP shunt in February 2013 at the NHNN. The shaving of my hair was easily the most traumatic part of the experience! By the time it had started to grow again I had found a setting on the shunt which provided sustained relief and I slowly began to get my life back. But not life as I knew it!"



"I am delighted to be supporting the efforts of the CSF Leak Association and only wish that when I was searching for answers, the resources and support they offer had been in place.

Since my leak I've developed chronic migraine which requires constant management and medication! My love of travel has been hindered by my shunt which goes a little crazy on flights any longer than 4 hours! I now exercise whenever I feel well enough, to keep my body fit and strong - just in case – I eat healthily and have even been known to meditate! All a far cry from that globe-trotting party girl I used to be!"



anterior MRI
coccyx cerebrospinal
epidural myelography
dura mater laminectomy
intracranial hypotension
blood patch thoracic CT
meninges pseudomeningocele

CSF Leak Terminology

Health-related terminology can be confusing at times, particularly to those without a medical background, with limited experience dealing with doctors or hospitals or who are new to a particular condition or illness.

Postural Orthostatic Tachycardia Syndrome / Postural Tachycardia Syndrome (POTS)

Postural Orthostatic Tachycardia Syndrome / Postural Tachycardia

We have prepared an alphabetical list of some of the most commonly used CSF Leak terminology on our website. Below is some of the terminology that start with P through to R. We will share further terminology in future editions.

Pia Mater

The pia mater, often referred to as simply the pia, is the delicate innermost layer of the meninges, the membranes surrounding the brain and spinal cord. The other two meningeal membranes are the dura mater and the arachnoid mater. Pia mater is a thin fibrous tissue that is impermeable to fluid. This allows the pia mater to enclose cerebrospinal fluid. By containing this fluid, the pia mater works with the other meningeal layers to protect and cushion the brain and spinal cord.

Pituitary Gland

The pituitary gland, or hypophysis, is an endocrine gland about the size of a pea. It is a protrusion off the bottom of the hypothalamus at the base of the brain, and rests in a small, bony cavity covered by a dural fold.

The posterior pituitary (is a lobe of the gland that is functionally connected to the hypothalamus by the median eminence via a small tube called the pituitary stalk. The anterior pituitary is a lobe of the gland that regulates several physiological processes (including stress, growth, reproduction, and lactation).

The pituitary gland is an important part of human anatomy and can be impacted upon by intracranial hypotension. In sufferers who experience significant sagging of the brain, the pituitary gland may appear misshapen or compressed.

Pledgets

Syndrome (POTS) is a condition of orthostatic intolerance in which a change from the supine/lying position to an upright position causes an abnormally large increase in heart rate, called tachycardia.

People with POTS have problems maintaining homeostasis when changing position, for example moving from one chair to another or reaching above their heads. Many also experience symptoms when stationary or even while lying down.

Symptoms present in various degrees of severity depending on the individual. POTS can be severely debilitating. Some afflicted individuals are unable to attend school or work and for especially severe cases, may be completely incapacitated. POTS symptoms can be very similar to those of Intracranial Hypotension and, accordingly, misdiagnosis can occur. Additionally, some CSF leak sufferers can develop POTS or a POTS-like condition, perhaps in part due to body deconditioning stemming from the inability to stand for anything more than a short period of time.

Pseudomeningocele

A pseudomeningocele is a collection of cerebrospinal fluid (CSF), normally located outwith the dura mater, which communicates with the CSF space around the brain or spinal cord. A pseudomeningocele normally has no surrounding membrane, but is contained in the space between the dura mater and surrounding soft tissues. Pseudomeningoceles are commonly found alongside a CSF leak, particularly high-flow leaks and those found on the anterior side of the spinal cord. Diagnosis of CSF leak may be possible where a pseudomeningocele is present, even if no specific leak site is found.

Radionuclide Cisternography

Radionuclide cisternography is an imaging technique which involves

Small wads of absorbent cotton or other soft material, which are inserted into the nose or ears to establish if CSF is leaking from those orifices.

Posterior

Posterior refers to the 'back' of the subject and is synonymous with dorsal, other than in the head. When referring to the body as a whole, the term 'dorsal' is used infrequently in human anatomy.

injecting a radionuclide by lumbar puncture into a patient's cerebral spinal fluid (CSF). It is used to determine if there is abnormal CSF flow within the brain and spinal canal and may also evaluate a suspected leak (also known as a CSF fistula).

You can view our full A to Z of terminology on our website, or download it in PDF format by clicking [here](#).



An important date for your diary...

The CSF Leak Association Annual General Meeting will be held on Wednesday 1st August at 19:00 via Skype. If you wish to attend, you will need Skype. You should contact us no later than 24 hours in advance of the meeting in order to book a slot. Please note that spaces are open only to members and your membership number will be required for confirmation. Spaces will be limited and will be given on a first come, first served basis. The AGM agenda and papers will be available in mid July.



If you would like to network with other CSF leak sufferers or their supporters, to share your experiences of the condition, diagnostic techniques and treatment options, why not head over to the Spinal CSF Leak Inspire community?

The Inspire Community is a safe, moderated forum co-managed by ourselves


and our friends at Inspire and the Spinal CSF Leak Foundation. You can choose to remain anonymous if you would like and have control over what information you divulge and how it is used.

You can access the community here: www.spinalcsfleak.inspire.com

Spread the word!

If you enjoyed this newsletter, why not share it on social media or email it to your friends?

 Share this newsletter on Facebook

 Tweet about this newsletter

 Forward this newsletter to a friend

 Pin this newsletter to your board



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