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Message from the Editor

Hello, <<First Name>>.

Welcome to the Spring 2020 edition of Leaker Life.

As the new Editor of our e-newsletter, let me briefly introduce myself. I'm a former Leaker, who was very unwell, and fortunate to have been repaired by neurosurgery in 2019. Volunteering for this charity is one way that my wife and I are able to "give back" and to help recognise my good luck. Call it "survivor's obligation", if you will. I have recently taken over editing responsibility from Polly Walker, who has done a superb job over the last three years to produce a great quality product. Polly will indeed be a hard act to follow!

As always, the Association has been incredibly busy in recent months. Two doctors were funded with bursaries to attend the SIH Conference at the Cedars-Sinai Hospital in Los Angeles. A first report of their exciting visit appears below. We still need to fill more positions on the Board of Trustees and to find enthusiastic volunteers to keep the work of the Association going. Please consider helping us, if you can.



As we were moving towards April, our household had been dominated by thoughts of the upcoming London Marathon. My wife Claire was due to proudly represent the CSF Leak Association, and hoping to raise plenty of sponsorship funds for our favourite charity. Now the coronavirus has caused the Marathon to be postponed, deferring her odyssey until 4th October. Please see the article below, and donate a little to the cause if you possibly can. Kind donations will help speed her over 26.2 gruelling miles!



Russell Secker

Volunteer e-newsletter Editor



An update from the Board of Trustees

With Covid-19 presenting a huge challenge for people across the globe and understandably dominating much of our health services' resources, we are acutely aware of the significant, and in many cases additional, struggles faced by those of us with ongoing CSF leaks and related health issues. It is a worrying and challenging time for many of us, and for many reasons.

In March, we worked with our Medical Advisory Committee to prepare [a statement on Covid-19 and CSF Leaks](#). There was, and remains, no clear evidence to suggest that having a CSF leak or a shunt, on their own, puts a person at higher risk. However, it is a

dynamic situation and there is much still to be learned about the virus, so it remains important to be cautious and maintain social distancing for as long as the Government wherever you are advises it.

What we do know is that those suffering from CSF leaks are likely to find it harder to cope with leak-related symptoms in addition to being ill due to a virus, especially if said virus induces coughing. If you are isolating with Covid-19 symptoms and you find your CSF leak symptoms are worse, please do speak to your medical team about it, so you can access what additional support may be available.

It is also important to note that there are some conditions that may be related to, or are sometimes seen alongside CSF leaks, that could potentially alter the picture for you. Some patient organisations related to these conditions have issued specific guidance and we would urge all who may be affected to consider the guidance and their health situation in the round, and to seek advice and guidance from their medical teams where there is any doubt.

In recent weeks, it has also become clear than many people in our communities with ongoing health conditions have been reluctant to access their usual sources for advice and support. Please, if you need medical support or advice, contact your specialist, GP or dial 111 (as appropriate). It is important that you should access help if you need it, rather than risk worsening your condition. Whilst most CSF leaks are not life threatening, they can be extremely debilitating and distressing and if you need treatment or support, please do ask for it.

Whilst many leakers have become masters of occupying themselves whilst stuck at home, with the advent of Covid-19 our family and friends may have found themselves with more time on their hands and are in need of a way to keep busy or find a new focus. We can help! We offer the opportunity of volunteering options that do not even require you to leave your home – the ultimate in social distancing.

We are looking for volunteers with social media, web design, secretarial, fundraising and volunteer management skills, to name but a few. We would invite anyone who feels able and willing to help in whatever capacity to note their interest with us. We understand, better than most, health-related limitations and competing priorities only too well, so we're always happy to work with you to find a task that fits with what you are able to offer.

We will be writing again in the not too distant future about volunteering, but in the interim, please do reach out to us, if you can. We'll also have a small social media campaign coming up for Volunteers' Week 2020, so please keep an eye out and share the information widely with friends, family and colleagues.

On a positive note, we are also pleased to report that our website passed the landmark of 1 million views since it was first launched in 2016! This is a wonderful achievement and bodes well for our current website redevelopment project, which we hope to complete over the next year. With the limitations of CSF leaks, we recognise that online engagement is fundamental to the work that we do. It is our principal 'shop window' and a vital way of helping the CSF Leak community. The existing website has served us well, but it is now showing its age so it is time to move forward.

Lastly, we would like to express our thanks and gratitude to Susan Iacovou, who joined us on the Board in 2019 and, latterly, took on the role of Acting Chair, but who recently stepped down due to ill health. She did a great deal of work on volunteer management, brought energy and enthusiasm, and her involvement on the Board will be missed. We wish her well for the future.

We hope that this edition of Leaker Life provides a useful distraction to lockdown and, remember, if you'd like a slightly longer distraction during lockdown, please contact us to volunteer!

David Baldwin

Acting Secretary

For and on behalf of the Board of Trustees



Claire Secker is preparing to run the 2020 London Marathon (now rescheduled to 4th October due to the coronavirus pandemic) to raise funds for our charity. To date, she has already been sponsored to the tune of £1,500. Here is her story:

"My husband Russell spent several years with an undiagnosed CSF Leak. In late 2018 he became severely unwell, and developed frontotemporal dementia. He was sleeping 18 hours a day, battling bad headaches, falling, choking, and losing his sense of smell and taste.

Luckily we were able to find a neurosurgeon who was able to successfully find and then repair his spinal leak. Since his recovery, we have both volunteered to support the CSF Leak Association.

This year, I will be proudly running the London Marathon to raise funds for the CSF Leak Association, so that it can continue to do fine work for sufferers, their carers and the broader medical community."



Please consider donating to this very worthy cause by clicking on the link below. Claire and Russ and the entire CSF Leak community truly appreciate any donations:

<https://uk.virginmoneygiving.com/fundraiser-display/showROFundraiserPage?userUrl=ClaireSecker1&pageUrl=1>



SIH Symposium 2020

Hosted by Cedars Sinai Hospital, Los Angeles - February 2020



Hi! My name is Linda D'Antona and I am one of the lucky recipients of the CSF Leak Association's 'Intracranial Hypotension Symposium' bursary. In this article, I will talk about my interest in CSF leaks and what I have learned about spontaneous intracranial hypotension (SIH) and CSF leaks at the Intracranial Hypotension Symposium that took place in Los Angeles last February.

First of all, a bit about me. I am a neurosurgery junior doctor and a final year PhD student at University College London. I have spent the past three years doing research on brain pressure at the National Hospital for Neurology and

Neurosurgery in London. A big part of my research focuses on SIH and low brain pressure. When I started my PhD in 2017 I felt that very little attention had been given to this complex disease. After reading papers and meeting patients with SIH, I started wondering: how is it possible that we know so little about a such debilitating and common disease? Hearing about the CSF Leak Association bursary, I thought it would be the perfect opportunity for me to meet the American experts on SIH and get the most up to date knowledge on this complex disease.

There is so much we still don't know about SIH and CSF leaks. First of all, what is the mechanism causing SIH? What is the best way to diagnose SIH and identify CSF leaks? Why we are sometimes unable to find a leak? What is the most effective treatment for CSF leaks? Why do some patients get better after an epidural blood patch whilst others never improve? Whilst the symposium could not answer these questions in full, it provided some very important information on new findings and advances in SIH. The next paragraphs describe the newest findings and theories about SIH and CSF leaks.

Diagnosis and misdiagnosis of SIH

SIH is more common than we were initially inclined to believe and the increase in awareness is improving our ability to recognise it.

Prof. Schievink and his team (Cedars-Sinai hospital, Los Angeles) are world experts on SIH and have diagnosed more than one thousand patients so far. They noticed a very interesting trend, which is that more patients are referred and investigated for suspected SIH compared to the past. This is very positive as it suggests that we are becoming more vigilant.

Unfortunately, misdiagnosis of SIH is still a serious problem. During the symposium various cases of SIH patients who were initially misdiagnosed were discussed. For example, SIH often gives the appearance of a 'sinking brain' on brain MRIs. This characteristic can very commonly be misinterpreted and lead to a wrong diagnosis of Chiari malformation. Another finding that can be misinterpreted is the SIH enlargement of the pituitary gland, as this can occasionally be mistaken for a pituitary gland disease. This is concerning, especially if we consider that some of the patients who are misdiagnosed receive invasive and unnecessary treatments. Additionally, Dr Gray (Duke University Medical Center, Durham) also shared her concerns regarding the numerous misdiagnosis of SIH as dementia or Alzheimer's disease. Cognitive impairment is not uncommon in SIH, and can improve with EBPs, therefore by labelling these patients with the diagnosis of dementia we would preclude them the possibility to be treated for SIH and to improve.

Another important issue raised at the symposium is the significant overlap between the symptoms of SIH and Postural Orthostatic Tachycardia Syndrome (also know as POTS). POTS should be considered as a possible alternative diagnosis in patients with orthostatic headache, especially when other imaging findings do not clearly fit with a diagnosis of SIH. Whilst the distinction between Chiari Malformation (or pituitary gland disease) and SIH can be achieved by an attentive analysis of the brain MRI scan and the patient's clinical presentation, the differentiation between POTS and SIH is more challenging. Appropriate autonomic tests are important for a diagnosis of POTS, but they are not always conclusive. A new study suggested that ultrasound of the optic nerve sheath can help differentiate between POTS and SIH in complex cases. This test looks at the diameter of the CSF that normally surrounds the optic nerve.

According to this recent study, and in contrast to POTS, SIH patients have a significant reduction of the CSF that surrounds the optic nerve when moving from flat to upright position. This study was based on a very small group of patients and the results will need to be confirmed with further research, however it is very promising and shows that non-invasive strategies to help distinguish between POTS and SIH are being explored.

Events like the Intracranial Hypotension Symposium and the activities of the CSF Leak Association are essential to further improve our ability to correctly diagnose SIH and CSF leaks. Further efforts should aim at improving the knowledge of junior doctors on this disease.

New imaging advances

Imaging is essential for both the diagnosis and treatment of SIH. Brain MRI should be considered our best ally for the identification of SIH patients, in fact it detects signs of SIH in about 80% of the patients. On the other side, spinal imaging is not as sensitive and despite the use of different spinal imaging techniques, many faculty members shared their struggle in finding a CSF leak in a significant proportion of patients (20-30%). Not being able to identify a CSF leak precludes patients from the possibility of being treated with targeted epidural blood patches or surgery. Two particularly interesting advances in the imaging of SIH were discussed: the cranial hyperostosis sign and the role of Digital Subtraction Myelography (DSM) for the recognition of CSF-venous fistulas.

Prof. Cutsforth-Gregory, neurologist at the Rochester Mayo Clinic, in a recent unpublished study found that some patients with SIH present skull thickening on brain imaging defined as the “cranial hyperostosis sign”. According to his theory, the reduction in CSF volume (or pressure) could facilitate further growing of the bone of the skull. Out of 310 patients included in the study, the cranial hyperostosis sign appeared in 40 (13%). I am looking forward to reading the full publication of this research, because if this sign is present in patients who do not have the other typical SIH brain imaging findings, it could significantly improve the overall sensitivity of brain imaging.

With regards to the spinal imaging techniques, Digital Subtraction Myelography (DSM) has been demonstrated to help the identification of the exact site of CSF leaks. This technique requires the injection of intrathecal contrast and imaging before and after the contrast is injected. It can be performed under sedation or general anaesthesia; this choice is made based on the radiologist’s preference and patient’s characteristic. Many of the faculty members agreed in saying that DSM is extremely useful especially for the detection of CSF-venous fistulas (type 3 CSF leaks). Moreover, according to Dr Kranz’s experience, a DSM performed in lateral decubitus (patient lying on the side) with a coordinated respiratory hold (Valsalva manoeuvre) increases the chances of identifying the CSF-venous fistula. DSM seems extremely promising, but further information will be needed on the role that these CSF-venous fistulas have in patients’ symptoms and the long-term outcomes of patients who had CSF-venous fistulas treated.

The ability to diagnose SIH and identify CSF leaks has clearly improved over the last few years. While we remain uncertain of which spinal imaging strategy is perfect, I am hopeful that new advances in artificial intelligence and upright MRI scanners will help to develop more sensitive spinal imaging techniques that will be less invasive and will expose SIH patients to lower radiation doses.

Treatment: best epidural blood patch technique and surgical management

SIH can be diagnosed based on the clinical presentation and imaging findings, even when the exact site of the leak is unknown. Moreover, several scientific papers demonstrate that blind epidural blood patches (EBP) work in a large number (but unfortunately not all) of SIH patients. This raises the question as to what the best treatment approach would be. Do we necessarily have to find the exact leak site before any EBP? Or shall we attempt treatment with a blind EBP first? This second option is preferred by Dr Dillon (from University of California San Francisco) and has the clear advantage of reducing the exposure of SIH patients to radiations as well as invasive spinal investigations. A similar strategy is employed by Dr Schievink's team: only a baseline brain and spinal MRI are performed before attempting the first EBP.

During the symposium, Prof. Louy (Cedars-Sinai hospital, Los Angeles) gave a comprehensive overview of the evidence on EBP in SIH patients. Several studies demonstrated that large EBPs (>20 ml) give better outcomes than small EBPs. Evidence also suggests that injecting the EBP at multiple levels is more effective than single level EBPs. While we still do not know why EBPs work in SIH, we could speculate that large and multi-level EBPs have higher probability of spreading over more spinal levels and therefore reach the CSF leak site.

One of the shortcomings of performing multi-level blood patches concerns the patients' experience. There are patients who find a lumbar EBP quite painful, I imagine that they would find it even more uncomfortable to undergo two EBP at different levels in the same occasion. A solution to this problem could be represented by the new single-catheter multi-level EBP technique proposed by Prof. Gemmete (University of Michigan Hospitals). This new technique is based on the insertion of a long catheter at a single spinal level. The catheter is then directed to all spinal levels and few ml of EBP distributed at each level. This technique achieves what we really want from an EBP: it allows the administration of large quantities of solution and ensures a good distribution to all spinal levels. I found this technique quite interesting and, if performed by expert hands, it could represent a valid strategy to obtain good outcomes with a single EBP.

Surgical repair of CSF leaks has a role in the treatment of patients who do not respond to EBPs. Dr Schievink has exceptional experience in the surgical treatment of CSF leaks and has developed techniques that allow him to reach and repair CSF leaks of different types in different locations. A very important message he shared during the symposium is that the exact location of the CSF leak needs to be known with certainty before performing any surgical treatment. This strategy reduces the need for invasive procedures that expose and explore large areas of the spine. Another important message is that while 98% of the patients operated have their leak successfully repaired (radiological outcome), this does not necessarily correspond to a clinical resolution of the symptoms. In fact, according to Prof. Schievink's experience, there are patients that achieve complete radiological resolution of the CSF leak after surgical treatment, but continue being symptomatic. Large databases collecting information on the long-term outcomes of patients treated with surgery could provide further guidance on the best treatment strategy to adopt.

What is the real problem in SIH and CSF leaks?

SIH has traditionally been considered as a syndrome caused by a spontaneous CSF leak in the spine, however, despite all the imaging advances, we are still unable to identify a CSF leak in 20-30% of patients with a clear SIH syndrome. A possibility that we should consider, is that maybe some of the patients with SIH do not have an active spinal leak.

Our understanding of the exact mechanism that leads to SIH is very limited, and this is not surprising considering that our knowledge on normal CSF dynamics is still very poor. During the symposium, Dr Moghekar (Johns Hopkins Hospital, Baltimore) went through several physiology concepts on CSF production, circulation and absorption. This talk clearly highlighted how most of the knowledge taught in medical schools on CSF physiology is incorrect. If we don't know how things work normally, how can we understand what happens in SIH? I think it is crucial that, while we work towards better imaging and treatment techniques for SIH, we simultaneously conduct research that can improve our knowledge of the mechanisms causing SIH. Dr Moghekar suggested that since CSF is 99% water, we should focus on monitoring the movement of labelled water in the brain through special imaging techniques.

A very interesting theory on the mechanism causing orthostatic headache in SIH was provided by Dr Silberstein (Thomas Jefferson University Hospital, Philadelphia). According to Dr Silberstein, SIH patients may have a problem of spinal dura compliance, consisting in the excessive ability of the spinal dura to relax and accommodate CSF. When SIH patients are upright, their spinal dura expands and accommodates an excessive amount of CSF causing low brain pressure and headache. The validity of this theory would be supported by the known association between SIH and connective tissue disorders and could be tested through the use of dynamic imaging techniques that observe the behaviour of the spinal dura in different body positions.

My take home messages

1 - SIH is a moving target.

The symposium demonstrated that research on SIH and CSF leaks is ongoing with great enthusiasm and that many new advances for the management of these conditions are achieved year by year. This is extremely encouraging, but it also demands that doctors caring for SIH and CSF leak patients should continue to keep up to date with the new findings in this field.

2 - Knowledge is power.

This symposium was a great opportunity for me to consolidate my knowledge on SIH and learn about the newest findings and advances. It also offered a simultaneous track of presentations especially dedicated to patients and caregivers. The activities of the CSF Leak Association (including this bursary) have been essential to raise awareness in the UK. Improving our knowledge on SIH and CSF leaks will allow us to improve our ability to recognise this condition and avoid misdiagnosis. I hope that in the future we will see more events raising awareness on SIH and that training and teaching activities for junior doctors will be implemented.

3 - Research can help answer the fundamental questions on SIH.

Something I particularly liked at the symposium was seeing how many doctors around the world share similar fundamental questions about SIH and CSF leaks. Why do people get SIH? Can we prevent it in some way? Is there always a CSF leak in SIH? Can we find a definitive cure for this disease? The symposium demonstrated that we are not simply focusing on the treatment and investigations for SIH, but we are also thinking about strategies to approach these important questions that will help SIH patients in the long run.

Most importantly, I would like to thank the CSF Leak Association for this amazing opportunity. The symposium gave me the chance to learn more from

world experts about SIH and my research will greatly benefit from this experience. I think the 'Intracranial Hypotension Symposium Attendance Bursary' is a very important initiative, and I hope that regular training events on SIH, similar to the Intracranial Hypotension Symposium, will start to take place also in the UK soon.

Linda D'Antona

Rare Disease Day 2020

Westminster Reception - February 2020

We had the pleasure of attending the Westminster Reception to celebrate Rare Disease Day. The annual receptions are hosted at the House of Commons in London, the Senedd in Cardiff, and the Scottish Parliament Building in Holyrood. Rare disease patients are invited to join politicians and other stakeholders in the rare disease community to mark Rare Disease Day 2020.

The speakers at the event were Liz Twist MP, Dr Jenny Harris the Deputy Chief Medical Officer for England, Amanda Brodie and Kristy Blakeborough-Wesson, both patients affected by a rare disease. After the talks we had the opportunity to engage with MPs, rare disease stakeholders and other members of our rare community.

Clare Sergeant

Headache Academy 2019

Royal College of Physicians, London - October 2019



The CSF Leak Association was delighted to be invited back to endorse and attend the 2019 Headache Academy at the Royal College of Physicians in London. It was the second specialist teaching weekend on headache disorders organised by Dr Matharu. The foremost headache experts in the country were invited to speak and give case presentations.

The aim of the event was to help clinicians to:

- Learn how to diagnose major categories of headache accurately
- Manage headache disorders more effectively
- Understand the evidence base for currently available treatments
- Develop effective, individualised treatment plans for patients.

In attendance were 120 delegates made up of Specialist Registrars in Neurology, Paediatrics, Emergency Medicine and General Practice along with Headache Specialist Nurses and researchers.

Clare Joy and I arrived early to furnish our stand with leaflets, posters and factsheets and after wrestling with the pop up banner which has a mind of its own we were ready for the delegates.

Opposite us were Shelly and Norma from Idiopathic Intracranial Hypotension (IIH) UK and it was a great pleasure to catch up with them and find out what their charity has been up to since we last met. We were pleased to see the sofas that had been such a comfortable resting place last year were still there but we were determined to do our best to listen to as many talks as we could from the packed program.

Dr Manjit Matharu (Consultant Neurologist, National Hospital for Neurology and Neurosurgery, London) began with an interesting introduction and overview of headaches, stating that they are common, highly disabling, often misdiagnosed

and under-treated. Effective treatment he said depended on correct diagnosis and as headache disorders have a large differential diagnosis they need to be approached systematically.

We were delighted to hear that due to the interest shown in Spontaneous Intracranial Hypotension (SIH) by the delegates at last year's Headache Academy, this year there was to be a dedicated presentation on SIH given by Dr Alok Tyagi (Consultant Neurologist, Queen Elizabeth Hospital Glasgow).

He began the presentation by describing conditions which can have similar symptoms to SIH, these being :

- Migraine
- Thunderclap headache
- Valsalva or Cough headache
- Positional rather than orthostatic headache
- Postural Orthostatic Tachycardia Syndrome (POTS)
- Colloid cyst

He emphasised the importance of establishing that the headache is definitely orthostatic as positional headaches can be confused with postural ones. He recounted a previous presentation by Dr Callum Duncan (Consultant Neurologist, Aberdeen Royal Infirmary). This was a case study of a patient who appeared at first to have classic symptoms of a leak, i.e. a postural headache which improved when lying down. After further investigation however, it was discovered the patient had a positional headache caused by occipital condyle syndrome. The patient's headache only improved when lying down on his left side rather than lying down in any position.

Dr Tyagi explained that orthostatic features can disappear with time so if a patient presents with chronic daily persistent headache he suggested asking what the headache was like when it first started to find out if there were orthostatic features at the outset.

He summarised the symptoms we are all familiar with then outlined the causes, these being: Surgical, Osteophytes or trauma. He noted the association spinal leaks have with Ehlers Danlos Syndrome particularly patients with lax skin and hypermobile joints.

He went on to say that although he would like to think that it was the acumen of neurologists that had led to an increase in patients being diagnosed with SIH but it was in fact due to advances in MRI scanning. The most commonly reported abnormality seen in SIH patients on an head MRI is diffuse pachymeningeal (dural) enhancements, followed by descent of the brain, enlargement of the pituitary, subdural fluid collections and engorged cerebral venous sinuses. He reported that 1 in 5 patients with SIH can have a normal MRI and the longer the duration of symptoms the less likely changes such as dural enhancements will be seen.

He advised that measuring CSF opening pressure is not a reliable method of identifying SIH as it can be normal in more than 60% cases but if a lumbar puncture needs to be done for other reasons and CSF pressure is measured and found to be less than 6cm water this would indicate SIH.

Dr Tyagi continued by describing three case studies:

- The first was diagnosed within days of onset and after one blood patch there was a complete recovery. This he stated was the desired outcome; early diagnosis and treatment leading to full recovery.
- In the second case it took longer to recognise the cause and two blood patches were needed to enable the patient to return to work. Although residual symptoms remained, the patient chose not to have a third patch at this time.
- In the third case several patches failed to give any significant relief. He stated this patient needed to be referred on to a specialist center with more experience of SIH.

He then set out the different types of spinal leaks stating that spontaneous leaks could be broadly classified into 4 types:

- Dural tears - usually ventral and less commonly dorso-lateral
- Meningeal diverticulum
- CSF Venous fistula
- Indeterminate / unknown

His take home message to the delegates was:

- SIH normally presents with orthostatic headaches but it can also present as chronic daily headaches.
- If SIH is suspected, ask for an MRI of the head with contrast.
- A lumbar epidural blood patch should be considered as soon as a diagnosis is certain.
- If there is no response to blood patches, send on to a Specialist Centre where they are better able to identify the site of the CSF leak and to treat with a targeted blood patch or surgery.

On the second day, Dr Jenny Pople came along to join me on the stand. It was a great pleasure to meet Jenny as I have long admired the work she does for the charity in producing the quarterly research review which is published on the CSF Leak Association website.

Watching the presentations gave an insight into the difficulties in diagnosing the different types of headaches and deciding on the appropriate treatment. We were encouraged by the requests for information about CSF Leaks and the genuine desire of the delegates to help those suffering with them. We were particularly delighted by the interest shown in the Charity's bursary to attend the 2020 CSF Leak Symposium in the USA .

We are extremely grateful to Dr Matharu for organising this event, inviting Dr Tyagi to give a presentation on SIH and for inviting the CSF Leak Association to attend. It has been an effective method of improving awareness of CSF leaks amongst the specialists who gave up their weekends to learn how to improve the healthcare provision to their patients. As knowledge of CSF leaks continues to grow, more people will benefit from quicker diagnosis and treatment, leading to increasing numbers of successful outcomes.

Clare Sergeant



Volunteer Clare Joy ready to meet delegates!



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?




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