

OKS newsletter

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Facebook page link [Otago Kidney Whānau | Facebook](#)



Welcome to the Otago Kidney Society (OKS) Summer 2024 newsletter

President's message

Welcome to Spring !

We had a great turnout to our last lunch at the Rope and Twine - it was lovely to see a few new faces. Keep an eye out for our next function coming up, and mention this to anyone in the kidney circle you think might benefit from a lunch out chatting with people who have similar experiences. If someone would like to come but may struggle with getting there please reach out we may be able to assist.

The OKS subsidised this by \$10 per person - we can only do this with the help of kind donations that we receive so many thanks to those who have been generous to the society.

We had our committee meeting after lunch with a few decisions made around stickers with our contact information on that will go onto flyers that will be placed for patients in the Outpatients area, dialysis Unit and other areas that will be useful for patients. We have also had our name and details put onto the Community services page. These changes have come about due to great feedback we have received about how hard it is to contact us. Our info@oks.nz is now working and we are now getting our messages. The step is to get a website up and running, we are working on this one step at a time.

Excitingly we have the Auto Spectacular coming up as mentioned before, this is a great opportunity for us to gather some much needed exposure and promotion of Kidney disease in our community, John Schollum will be speaking so come along and give him your support. We will also have a table with

some committee members and pamphlets for educating the public, we hope that you can come along and say hi and support the OKS- any help always appreciated.

We are always looking for an extra set of hands or minds to contribute to the OKS please reach out if you would like to join the committee

"Despite the forecast, live like its spring" (Lilly Pulitzer)

James Blair

Events

Otago Kidney Society Winter Lunch

We had a good attendance at our recent OKS lunch on August 11th with 20 people attending. It was great to see some new faces as well as many familiar ones. It was a beautiful sunny day and we all enjoyed a leisurely lunch at Rope & Twine in Dunedin, with plenty of time to chat and to exchange ideas & experiences.

The provisional date for our Christmas Lunch is Sunday, 1st December and the venue will be somewhere in North Otago, possibly Moeraki. Details will be sent out shortly.

We're aware that our members come from all over Otago & Southland & so try to vary the locations to suit everyone.

If anyone would like to attend a lunch but has no transport please get in touch & I'll do my best to organise some for you.



Also, if any of you that are planning to attend and have room for a couple of extra people and would be happy to transport an extra person or two please also let me know.

I look forward to seeing as many of you as possible at our Christmas lunch.

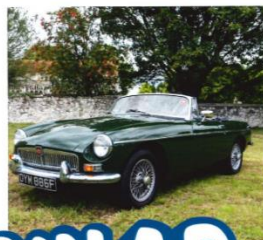
Liz Edwards

Photos from our Winter lunch





T.C.P.
TAKING
CARE OF
PIGMENT
LASER TATTOO & PIGMENT
REMOVAL SPECIALISTS



AUTOSPECTACULAR Dunedin 2024

This year's charity is
Otago Kidney Society



EDGAR SPORTS CENTRE

SATURDAY 19 OCTOBER 2024, 9AM - 4PM

\$10 ENTRY \$20 FAMILY



\$1000 TYRE VOUCHER DOOR PRIZE BRIDGESTONE SELECT DUNEDIN

Organised by: Otago Classic Motoring Club Inc. & Otago
Falcon & Fairlane Club Inc.
Email: roblovespigs@gmail.com for entries
Email: ashleyboorer@gmail.com for information
Otago Kidney Society: natalie@windersbrown.co.nz

CLUB DISPLAY THEME: WEDDINGS

SPECIAL FEATURES
100 YEARS OF MG
60 YEARS OF MUSTANG
110 YEARS OF DODGE
KIDS TOYSPECTACULAR

SPONSORS

Dunedin Auto Electrical
T.L. McLean Ltd
Leviathan Hotel
Dunedin Head Systems Ltd
W. Rietveld (Otago) Ltd
Dexion Supply Centre
Everitt Enterprises
Steve MacPherson Earthmoving
Honda Store Dunedin
Blair Welsford Ltd

Taking Care of Pigment
McFarlanes Tyre Service 2017 Ltd
Triple RRR Ltd T/a Roscoes
Pit Stop Dunedin
Colour Connection
Exit Funeral Services Ltd
All Car Services
Hydraulic Services & Repairs Ltd
Otago Towing 2020 Ltd
Clements & Stephens

A1 Auto Spares
R.J.P Paint & Panel Supplies
Bridgestone Select Dunedin
Active Fabricating Ltd
Sims Brakes Services Ltd
Douglas Body Works Ltd
VINZ Vehicle Inspection NZ
Foley Plumbers Ltd
Peterson Fabrication Ltd
Aburns Glass 2005 Ltd

Introducing our new Committee Member Gail Kilkelly



When Gail found out from Liz that we had a shortage of committee members she put her name forward and joined our team at our June Committee meeting, much to the delight of the rest of our committee.

‘ My Husband Kev got very ill with a virus back in 2015 and after being admitted to hospital the doctors couldn’t his save the kidneys. Kev ended up with Vasculitis and needed a kidney transplant. That in itself proved a challenge in the Nephrology world. (Prof Walker wrote a paper for the global nephrology team about this). Two Days after the transplant the vasculitis reared it’s ugly head and wanted to destroy the new kidney. This ended up with Kev having several full body plasma exchanges. Through our whole journey including the transplant we could not fault any of our medical team in Dunedin or Wellington. I was looked after very well also. We owe our Health System/Board/Teams and especially Nephrology & Kidney Society a great debt. So what better way to give back than to become a member of the OKS.

Kev & I have 2 children, 3 Grandchildren and now a great grand child. We live in Omakau & we run a concrete cutting and drilling business from Alexandra working mainly in the Queenstown Lakes District areas.

I also own the Omakau RD, 2 Rural Postie runs for Omakau –

Lauder – Becks. This keeps us both pretty busy but never too busy for our Friends & Family and also like giving back to our community through various ways.'

Gail Kilkelly



Update from Kidney Health New Zealand (KHNZ) Update from Kidney Health New Zealand

KHNZ has recently launch a new Digital Information Assistant called Kiri which is available on their website (<https://www.kidney.health.nz/kiri>)

Kiri provides 24 hour access to information and resources related to CKD, ESKD, Renal Replacement Therapies such as Dialysis, Kidney Transplantation and loads of other related topics. The information provided has been curated and screened by the team at Kidney Health New Zealand and comes from trusted, credible sources. It can be relied on to be up-to-date and accurate.

Visit the KHNZ website and give Kiri a go. Their team of Nurse Educators are also available if you need more in-depth information or you'd just like to talk to a real person. You can contact the Nurse Team on 0800 543 639 during normal business hours.

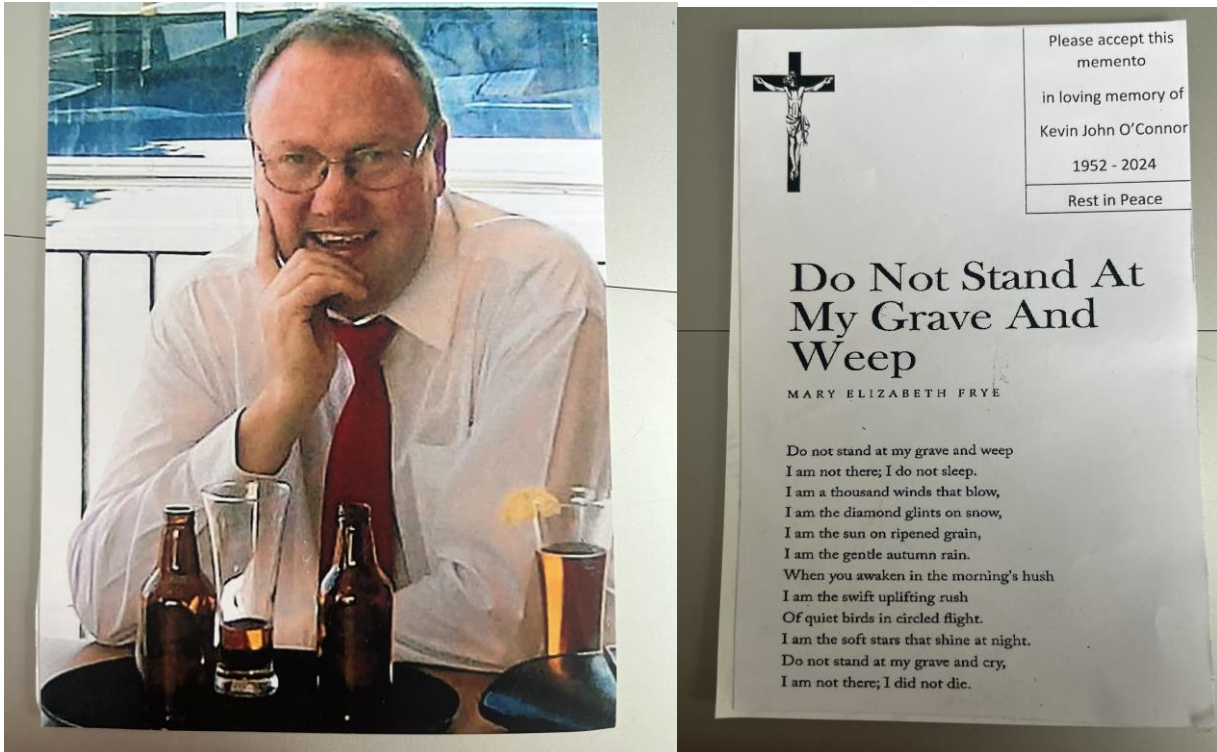
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Farewell to Kevin O'Connor



It was with much sadness that we said goodbye to Kevin earlier this month. I had the privilege of attending Kevin's funeral and it is always wonderful to learn so much about someone that you have worked with on a committee but didn't know anything about them. It was lovely to hear of his loving relationship with his wife and family and the happy times they shared.

Also to find out a bit more about the man who was keen to help on OKS and it was not surprising that he put his hand up as he was always doing things to help others in the community. Kevin worked at New World when he was on the committee and was instrumental in getting grocery vouchers for patients, hopefully you may be one of the lucky people that benefitted from his kindness.

Kevin was fortunate to get a kidney from his cousin Louise, which was such a wonderful gift and freed him from doing Haemo Dialysis at home.

Natalie

A message from our new Charge Nurse Manager Southern Dialysis Service Nic Holborow

Kia Ora all!

Thank you for the invite to introduce myself to you all as I step into the role as the Charge Nurse Manager of the Southern Dialysis Service.

I am a Southern girl born and bred and very proud of my Te Wal Pounamu roots! I am a fierce advocate of providing accessible, welcoming, kind and compassionate care to all of our patients and their whanau and ensuring we have a service that our nursing and medical staff love working in.

My nursing background is predominately in Emergency Nursing where I have worked for the past 15 years, both in New Zealand and Australia. I have also been fortunate to work in Oncology and Haematology both here and in London.

While Dialysis is a new area for me, I can see similarities between ED due to the collegiality and respect between the medical and nursing teams as well as nurses working top of scope and being experts in their fields. We have an incredible team here in the south.

Out of work I am a mum and a wife and love to spend any spare time with my Tūrangawaewae (Central Otago) by a Lake or on a Mountain.

I look forward to meeting you all over the coming months

Nic Holborow

Charge Nurse Manager

Southern Dialysis Service

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The
STEP-PD
AKTN 24.01 Trial

We're excited to announce a consumer involvement opportunity for a trial-in-development, the STEP-PD Trial!

Currently, most people starting peritoneal dialysis, or PD, begin with the full treatment schedule, which is a commitment of 24 hours a day, 7 days week. The STEP-PD trial will explore whether starting PD with a personalised, reduced schedule, leads to better quality of life, including improvements in pain, energy and social activity levels.

What is involved?

- **60 minutes** of your time.
- You'll spend that time in a **zoom call** with a group of participants with lived experience of peritoneal dialysis (PD).

There will be some pre-reading required, but no particular knowledge is needed.

You'll be asked to review a draft Participant Information & Consent Form (PICF) and asked for your opinion on how clearly written and informative it is.

You'll also be invited to share your ideas on how the PICF might be improved so that potential trial participants can make a *genuinely* informed decision about whether to take part.

The possibility of having participants provide their consent online will also be discussed.

Who are we looking for?

- Up to ten (10) adults who have had experience with peritoneal dialysis (PD) in the last five years.
- Your experience is as a patient **or** a caregiver.

Will you be paid for your time?

We can offer remuneration for your involvement, via a deposit into your bank account or digital gift card, to the value of AUD \$50.00 per hour.

If you'd like to be involved, please:

Indicate your interest via reply email as soon as you can - just [click here!](#)



Please get in touch if you have any questions.

Thank you for considering this opportunity!

Hayley Candler, AKTN Consumer Engagement Coordinator

Some interesting developments in the pharmaceutical space from Apellis

‘At Apellis, we combine courageous science and compassion to develop life-changing medicines for some of the most challenging diseases patients face. ‘

Release Details

Apellis and Sobi Announce Positive Topline Results from Phase 3 VALIANT Study of Pegcetacoplan in C3G and Primary IC-MPGN

August 8, 2024

- *Met the primary endpoint, achieving statistically significant 68% ($p<0.0001$) reduction in proteinuria compared to placebo in a broad study population*
- *Positive results consistent across all subgroups, including C3G and IC-MPGN, adolescent and adult patients, and native and post-transplant kidneys*
- *Demonstrated favorable safety, consistent with established profile*
- *Companies plan to submit data for regulatory approval in the US and EU*

WALTHAM, Mass. and STOCKHOLM, Aug. 08, 2024 (GLOBE NEWSWIRE) -- Apellis Pharmaceuticals, Inc. (Nasdaq: APLS) and Sobi® (STO: SOBI) today announced positive topline results from the Phase 3 VALIANT study investigating systemic pegcetacoplan in patients with C3 glomerulopathy (C3G) or primary immune complex membranoproliferative glomerulonephritis (IC-MPGN), which are rare kidney diseases with no approved treatments. The study met the primary endpoint, demonstrating a statistically significant and clinically meaningful 68% ($p<0.0001$) proteinuria reduction (log-transformed ratio of urine protein-to-creatinine ratio) in C3G and IC-MPGN patients treated with pegcetacoplan compared to placebo, both in addition to background therapy, at Week 26. Results were consistent across all subgroups, including C3G and IC-MPGN, adolescent and adult patients, and native and post-transplant kidneys.

Pegcetacoplan also demonstrated statistical significance on the key secondary endpoints of composite renal endpoint, which combines proteinuria reduction and estimated glomerular filtration rate (eGFR) stabilization, and proteinuria reduction of at least 50% compared to baseline, as well as nominal significance on the histological endpoint of reduction in C3c staining on kidney biopsy and stabilization of kidney function as measured by eGFR compared to placebo.

“As a clinician, I’m thrilled by these groundbreaking results, which show that pegcetacoplan has the potential to significantly improve the lives of patients with C3G and IC-MPGN, regardless of disease type, age, and transplant status,” said Carla Nester, M.D. MSA, FASN, lead principal investigator for the VALIANT study and Jean E. Robillard M.D., professor of pediatric nephrology, University of Iowa Stead Family Children's Hospital. “Currently, many patients living with these rare diseases will eventually require a kidney transplant or lifelong dialysis, so there is an urgent need for a treatment that targets the underlying cause of these diseases. These positive data are a major advance for the rare kidney disease community.”

“These results exceeded our already high expectations. Pegcetacoplan is the first investigational therapy to show such a strong reduction in proteinuria in C3G and IC-MPGN with supportive data across multiple measures of disease activity,” said Jeffrey Eisele, Ph.D., chief development officer, Apellis. “Building on pegcetacoplan’s approval in PNH, we look forward to sharing these data with the FDA and working quickly to bring this treatment to patients with these debilitating kidney diseases.”

"Today’s announcement further strengthens our belief in pegcetacoplan’s potential to meet the critical needs of patients with these severe and life-threatening kidney conditions," stated Lydia Abad-Franch, M.D., head of R&D, medical affairs, and chief medical officer, Sobi. "We remain committed to progressing pegcetacoplan's development and expanding its reach, driven by our steadfast mission to transform the lives of those affected by rare diseases."

In the VALIANT study, pegcetacoplan demonstrated favorable safety and tolerability, consistent with its established profile. Rates of adverse events (AEs), serious AEs, and AEs leading to study drug discontinuation were similar between the pegcetacoplan and placebo groups. There were no cases of meningitis or serious infections attributed to encapsulated bacteria.

All patients who have already completed the VALIANT study have now enrolled into the VALE long-term extension study.

Apellis plans to submit a supplemental new drug application to the U.S. Food and Drug Administration in early 2025. Sobi also plans to submit a marketing application with the European Medicines Agency in 2025. Detailed data will be presented at an upcoming medical congress.