

INFORMATION

Inflammatory Neuropathy Support Group of Victoria Newsletter



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Newsletter of the 'IN' Group: THE INFLAMMATORY NEUROPATHY SUPPORT GROUP OF VICTORIA INC., supporting sufferers from acute Guillain-Barre` Syndrome (GBS) & Chronic Inflammatory Demyelinating Polyneuropathy (CIDP) and other Inflammatory neuropathies.
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PRESIDENT'S REPORT TO AGM 2023

Firstly, I'd like to welcome Adelaide Krania, Philanthropy Coordinator, the Royal Children's Hospital Foundation to the meeting.

I am happy to report another good year for the IN Group.

We have calls from people asking advice and assistance. They often just need someone to talk to.

The website is used by many, our newsletters are posted on the site which has information and details for contact.

The committee does a great service and keeps the quarterly meetings running well with very interesting speakers and also manages a wonderful luncheon at our end of year function.

A thank you also to our Doctors who support us and attend when possible plus the staff from the Children's Hospital who visit and speak at meetings.

The newsletter contains wonderful information and it is a big thank you to Margaret Wilson who spends many hours getting it ready to publish quarterly.

I wish to thank the committee for many years of service to the Group, and especially to me, as they are all so willing to assist in so many ways.

My last thank you is to the wonderful members who give so generously with donations to the research programme.

With grateful thanks.
Margaret Lawrence
President



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TREASURER'S REPORT TO AGM

For the twelve months ended 30th June 2023

Income for the year was up by \$3,360 to \$10,910. The major items of income movement were Subscriptions up \$450 and Donations up \$2,428.

Expenses were lower than last year by \$199.

A donation of \$10,000 was given to the Royal Childrens Hospital via Assoc. Professor Andrew Kornberg, to be used for research purposes.

Net Result for the year was a cash deficit of \$805 and when reduced from the carried forward balance from the previous year, the Equity as at 30th June 2023, was \$19,356.

Since the beginning of the IN Group in 1992, we have donated \$175,000 to the Royal Childrens Hospital for research.

I wish to thank all members once again for their support and most generous donations over the past year.

Doug Lawrence
Treasurer

COMMITTEE FOR ENSUING YEAR

The following members were elected unopposed:

President	Margaret Lawrence
Vice President	John Burke
Secretary/Treasurer	Doug Lawrence
Committee Members	Melva Behr, Brian Boyd Mary Clarke, Gwen McInnes, Janice McNamara

Membership Renewal

If you have not yet renewed your membership subscription for this year, please use the form on the last page.

Donating to the IN Group

The IN Group is a registered charity and as such any donations you make of \$2.00 or over are tax deductible. It is easy to donate when you renew your annual subscription.

However, we have recently received advice that there is another way that you can make an online donation. When you make a purchase via *PayPal*, you may opt to donate to your chosen charity when finalising your payment.

The donation is facilitated via the *PayPal Giving Fund* which is a public ancillary fund and charity registered with the Australian Charities and Not-for-Profit Commission, and forwarded to the IN Group bank account. The group has recently received donations this way.



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Victorian SCIg Access Programme 20th August 2023

Compiled from speaker notes and a recording taken at the presentation.



Anne Graham
Blood Matters Project Nurse (SCIg)
Victorian Department of Health & Australian Red Cross
Lifeblood

Anne Graham works with the Australian Red Cross Lifeblood in partnership with the Victorian Department of Health as the Project Nurse for the Victorian Subcutaneous Immunoglobulin (SCIg) Access Program.

As well as assisting health services to commence and expand hospital SCIg programs, her role also includes raising clinician and patient awareness and knowledge of SCIg.

What are immunoglobulins?

Immunoglobulins are also known as antibodies. They are a typical part of our immune defence system and are produced by a particular type of white blood cell named plasma cells which protect the body from infection caused by toxins, bacteria, and infection.

How are immunoglobulins made?

Immunoglobulins are made from donated human plasma and each batch requires thousands of donations. Many products are made from these plasma donations including IVIg and SCIg. Ig manufacture is strictly regulated to ensure safety; it has been used for many decades and has an excellent safety record.

Who needs immunoglobulin therapy?

IVIg and SCIg are generally used for replacement therapy – providing additional immunoglobulins to patients who do not make enough of their own to maintain a healthy immune system. And immunomodulation therapy – supporting patients with a range of autoimmune disorders by preventing their immune system attacking its own body.

What is the difference between SCIg and IVIg?

This slide was prepared by Anne and reproduced with permission.

	SCIg	IVIg
Who can have it?	Meet SCIg criteria	Meet IVIg criteria
Where?	Patient’s home – self or carer administered	Hospital – health professional administered
Route	Subcutaneous; abdomen, thigh, upper arm	Intravenous
Lifestyle	Can be administered at a convenient time. Gives more flexibility and independence. Fewer hospital visits, less expensive	Required to attend hospital every month. Arranged by hospital staff
Education	Must learn to insert subcutaneous needle, draw up product, use pump, document event	Report any reactions
Duration of infusion	Approx. 1 hour per infusion – varies depending on dose, number of sites and product	2 – 5 hours per infusion



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Frequency	Daily, weekly, fortnightly – varies depending on dose	Usually monthly
Health effect	Consistent, steady Ig levels, no wear off effect	High peaks and low troughs, wear off effect can start up to 1 week prior to next infusion
Side effects	Local side effects: site swelling, redness and itching at the injection site(s), Can last 1 – 2 days. Lower risk of systemic side effects	Systemic side effects; during and post infusion Headache, nausea, flushing shivers, itch, and fatigue Can last up to 3 days post infusion
Travel	Can administer SCIg while travelling	Can be difficult to arrange treatment overseas

What are the pros and cons?

The Australasian Society for Clinical Immunology and Allergy (ASCI) has released a position statement on the pros and cons of IVIg and SCIg therapy including:

	Pros	Cons
IVIg	<ul style="list-style-type: none"> <input type="checkbox"/> Less frequent infusion (monthly) <input type="checkbox"/> Rapid increase in serum IgG <input type="checkbox"/> Does not require patient training 	<ul style="list-style-type: none"> <input type="checkbox"/> Usually hospital based. <input type="checkbox"/> IV access required. <input type="checkbox"/> Risk of immediate and systemic adverse effects <input type="checkbox"/> Adverse effects from high IgG levels in 12-48 hours post infusion. <input type="checkbox"/> Symptoms related to wear off effects of IgG trough levels
SCIg	<ul style="list-style-type: none"> <input type="checkbox"/> Home based therapy. <input type="checkbox"/> IV access not needed. <input type="checkbox"/> Few systemic side effects. <input type="checkbox"/> Can be used for patients with previous systemic reactions to IVIg or IV access difficulties – SCIg therapy may be the preferred treatment in these patients. <input type="checkbox"/> Shorter infusion duration <input type="checkbox"/> More consistent IgG levels with no wearing off effects related to IgG trough levels. <input type="checkbox"/> Improved QOL for patient and family with flexibility, independence, and empowerment <input type="checkbox"/> Reduced hospital costs <input type="checkbox"/> Reduced patient travel time and associated costs and inconvenience (e.g. time off school/work, parking costs) <input type="checkbox"/> Patient can take treatment with them when travelling (e.g. on holiday) 	<ul style="list-style-type: none"> <input type="checkbox"/> Frequent administration (1-3 times per week) <input type="checkbox"/> Local side effects (swelling, induration, local inflammation, itch) which are usually mild and transient. <input type="checkbox"/> Some patients may require battery or spring driven pumps, although some patients may use the rapid push method which does not require a pump. <input type="checkbox"/> Requires treatment plan compliance

What are the approved indications?

There are five approved indications for SCIg in Australia:

- Three immunology indications approved in 2013 – primary immunodeficiency diseases with antibody deficiency; specific antibody deficiency and secondary hypogammaglobulinaemia unrelated to haematological malignancies, or post-haemopoietic stem cell transplantation .
- One haematology indication approved in 2013 – acquired hypogammaglobulinaemia (a disorder caused by low serum immunoglobulin or antibody levels) secondary to haematological malignancies, or post-haemopoietic stem cell transplantation.
- One neurology indication approved in 2019 – Chronic Inflammatory Demyelinating Polyneuropathy, CIDP.

Suitability of SCIg

Not all patients will want treatment with SCIg but there are many patients who do choose SCIg as their treatment choice and prefer it to IVIg. For those that would like to administer SCIg they must be willing to prepare the SCIg and administer it themselves, or have a carer do it for them, so they must have the manual dexterity to be able to do this.



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Patients who are most suitable for SCIg are those who would like more control, flexibility, and autonomy with their treatment – some patients would rather administer their SCIg on a Friday night while watching a movie than sit in a hospital for up to 5 hours having treatment with IVIg.

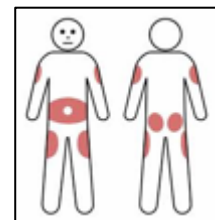
Patients who need to travel a long distance for treatment in hospital with IVIg - frequently this can be regional patients who have treatment in a hospital in Melbourne. Also, patients who don't have time for treatment in hospital – this can be due to work or education and SCIg can save this continual time away from work and school.

Patients who wish to travel interstate or overseas for an extend time are able to continue treatment with SCIg while on holiday rather than missing treatment with IVIg. There are also patients who are difficult to insert the drip for IVIg and patients who have reactions from IVIg may find treatment with SCIg more suitable.

How is SCIg administered?



Infusions are given using a special pump by slowly injecting the SCIg into the fatty tissue just underneath the skin in any of the areas indicated in the diagram at right.



Infusions can be weekly, fortnightly, or more frequently if required depending on dose and the number of needles used.

By having treatment more frequently the immunoglobulin levels are more stable and consistent rather than the peaks and troughs associated with IVIg.



Note the very fine needle.

Arranging accessibility for SCIg

Patient confers with doctor and a decision is made to administer SCIg → Approval for SCIg? yes/no
 → Patient receives self-administration education → Patient receives prescription for SCIg from treating doctor → Patient receives consumables from SCIg nurse → Patient has ongoing reviews with treating doctor/SCIg nurse.

Consumables provided to the patient include a special bin for disposables returned to the hospital to be safely disposed of.

SCIg patient education

The SCIg patient education is very comprehensive whether it is from the hospital SCIg nurse or through the *CSL Cares* patient programme or the *Takeda atHome* patient programme. The patient will continue to receive education and support until the educating nurse and the patient are sure that the patient is confident and competent to administer themselves.

The education will cover the equipment and consumables required to administer the SCIg as well as the areas where the SCIg can be administered. How to transport and store the SCIg will be explained, and the patient will be taught how to prepare and administer the SCIg. Patients will also be informed about potential reactions to SCIg and how to manage them e.g. infusion site reactions. The infusion details are required to be documented.



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Required documentation recording

There are a couple of ways to record the infusion details – writing in an infusion diary or by recording on an infusion app on a smart phone.

Details that are usually recorded are -

Product name; Batch number; Dose; Volume; Infusion time; Infusion site; Infusion rate; Symptoms and/or side effects

Resources available to support patients

There are some SCIg patient resources available on the Blood Matters webpage -

<https://www.health.vic.gov.au/patient-care/subcutaneous-immunoglobulin-sci-g-access-program>

Patient resources include:

- 2 A3 SCIg promotional posters – 1 is aimed at people with an immunodeficiency and the other is for people with CIDP.
- A conversation starter which can be used by clinicians to introduce patients to SCIg. It gives patients an overview of SCIg and explains the differences between intravenous and subcutaneous administration.
- And as many patients travel with SCIg there is a travel guide which assists patients, SCIg nurses and treating specialists prepare for overseas holidays.

Other supports

Recently the Australian Primary Immunodeficiency Patient Support, known as AusPIPS, in collaboration with other organisations has developed a patient-centred brochure explaining immunoglobulin therapy for patients receiving this treatment both intravenously and subcutaneously. This patient brochure is available in 7 languages and there is also an Auslan translation - <https://www.auspips.org.au>

The *Takeda Cuvritru atHome* patient support programme is available to all patients administering *Cuvritru* while the *CSL Behring Cares* patient support programme is available for all patients administering *Hizentra*, *Evogam* and *Hizentra AU*. Both programmes can be accessed via a referral from the treating clinician or the SCIg Nurse and patient education will be given in the patient's home by a Nurse trained in SCIg administration. Both *CSL* <https://hcp.cslbehring.com.au/> and *Takeda* www.takeda.com have a suite of SCIg resources for patients.

How to access SCIg?

Many public hospitals have established SCIg programmes, giving patients a treatment choice. These programmes have a SCIg Coordinator/Nurse who coordinates the programme and ensures everything runs smoothly. These specialist SCIg nurses can educate patients, or their carers how to administer SCIg, or public hospitals can arrange with *CSL Behring* and *Takeda*, to have their patient support nurses provide the patient education.

Until recently privately funded hospital patients have not had the choice of treatment with SCIg, however there is now an in-home nursing service – *National Home Nurse*, (NHN) in Victoria, which is approved to educate patients, in their own home, on how to administer SCIg. On approval from the relevant health fund *NHN* will supply the SCIg equipment and ongoing consumables for home administration. Arrangements will be put in place for SCIg dispensing. Once the patient is competent to self-administer *NHN* will continue to follow up with them and the treating doctor. Patients will continue to see their treating doctor for review as required.

At this stage in her presentation Anne welcomed questions -



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Q What does it cost?

A There is no cost to the patient for the product. Initially SCIg was not well taken up in Australia but following successful lobbying by AusPIPS the health department agreed to fund its use.

Q Is it up to medical staff to determine if someone needs it?

A Yes it is decided by a doctor if treatment with immunoglobulin is required and then the patient and doctor can decide whether it will be IVIg or SCIg . Sometimes doctors do not always have a great knowledge of the SCIg program process so it is quite OK to contact the hospital SCIg Nurse who will be able to provide further information on the process. Monash Health has a very good SCIg programme also St Vincent's public hospital.

Q What about regional hospitals?

A Yes, for example Wimmera Health has a SCIg programme.

Q What cost saving is there to the government in providing home-based equipment?

A Currently, the cost of the service is paid by government through additional payments to SCIg services covering all equipment and consumables, but no official cost/benefit analysis has been done to date. Monash Health is carrying out an analysis, but results are not yet available. Information which is available shows that there is some cost savings –

- fewer infections from administration of the infusion
- Patients using SCIg at home frees up a hospital chair for IVIg, blood donation, transfusions, and other procedures.

Q Is there a limitation of production?

A Production is basically the same as IVIg. There are Australian donors, but the demand is much higher than supply. *CSL Behring* uses domestic and imported plasma. *Takeda* uses imported plasma only.

Q Is the volume less because it is split between two operations?

A No, not really as there are still the same number of patients and the same level of supply. Once you have qualified for therapy you have a choice, and that does not mean less supply available for either treatment.

Q If you elect to go on to SCIg can you return back to IVIg?

A Yes. Patients are provided with a maximum of 2 months supply. initial supplies are restricted to 1-2 weeks so that there is no wastage should a patient wish to return to IVIg therapy.

Q In any one treatment can you use more than one infusion site?

A Yes, you can use up to 4 needles at one time. The more needles you use, the less time it takes to administer the infusion. CIDP patients can have up to 200ml – 50ml in each of 4 sites. But, for example, two pumps could run eight needles!! SCIg is viscose so is pushed through the needle slowly. An adaptor attached to the pump can be set to vary the dose rate.

Q Does the product need to always be refrigerated?

A Not always, but with climate fluctuations (heating, sunlight etc), to protect the integrity of the infusion, it is better to keep it in fridge at 2-8 degrees. It's always a good idea to refer that type of question to the manufacturer.

In conclusion, Anne emphasised that most importantly SCIg treatment is focused on the patient. It is a patient centred treatment choice that offers eligible patients an alternative to intravenous immunoglobulin. SCIg provides more stable and consistent immunoglobulin levels with less reported peaks



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and troughs - often seen with IVIg. Patients have reported feeling better for longer with no “wear off-effect”.

It is a collaborative partnership between the treating doctor, patient, health service and dedicated SCIg nursing staff. It allows eligible Victorian patients to have a choice regarding their treatment modality which in turn offers patients autonomy, a sense of empowerment, flexibility, and independence. It can be administered at a time that fits into the patient’s routine and lifestyle often improving a patient’s work life balance.

Being a home base treatment means fewer visits to hospital which in turn equates to less time off work or school, less expense in parking and travel costs.

It can be administered daily, weekly, or fortnightly with the duration of infusion being approx. 1 hr depending on the dose, product, and the number of injection sites.

It is well tolerated with a favourable safety profile. Side effects are reported to be localised swelling, redness and itching at the injection site. This is often transient and can last for 1-2 days. There is very low incidence of systemic side effects that can occur with IVIg such as headache, fatigue, nausea etc. SCIg treatment has resulted in fewer hospital admissions due to infections and less antibiotic use.

Feedback from patients demonstrate an overwhelmingly positive trend for SCIg and most importantly SCIg has been described as life changing by some patients.

There was great interest then by members in the demonstration Anne gave of how the self-administration infusion worked.

She invited members to contact her with any further questions about the SCIg service.

Contact: Anne Graham
Blood Matters Project Nurse
Blood Matters SCIg information, tools, and resources
Phone: 03 9694 0126
Email: BloodMattersSCIg@redcrossblood.org.au

SCIg has been approved for the treatment of CIPD since August 2019 and is a safe, effective, and well-tolerated alternative treatment option to intravenous immunoglobulin (IVIg).

You can always find out more on the Blood Matters SCIg webpage which has patient information and other resources:

<https://www2.health.vic.gov.au/hospitals-and-health-services/patient-care/speciality-diagnostics-therapeutics/blood-matters/immunoglobulin-replacement-therapy/scig-implementation-program>

PREFER TO RECEIVE YOUR NEWSLETTER IN HARD COPY?

As you know the IN Group’s preferred method of communication is by email, and you may currently receive all communications in that form but would prefer to receive your newsletter in hard copy. This can be arranged if you will email that request to - info@ingroup.org.au

NEXT MEETING DATE TO REMEMBER

Sunday 10th December 2023 12noon Ashburton Library Christmas Lunch
This is always an enjoyable and fun-filled day – we look forward to seeing you then.



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**The Inflammatory Neuropathy Support Group of Victoria Inc.
Membership 01.07.2023 – 30.06.2024**


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NOTE: The IN Group’s preferred communication is by email.

If you wish to have your Newsletter sent in hard copy please tick here:

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