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INFORMATION

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26 Belmont Road,
Glen Waverley, 3150
Victoria, Australia

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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

THE NEXT MEETING WILL BE OUR ANNUAL GENERAL MEETING

TO BE HELD ON 24TH AUGUST, 2018 FROM 2-4PM

AT THE BALWYN LIBRARY,

WHITEHORSE ROAD, NORTH BALWYN

COMEDIAN, DON JONES WILL ENTERTAIN US.

PLEASE INVITE YOUR FRIENDS AND FAMILY TO JOIN US.

A small plate to share would be appreciated. Thank you.

RSVP: MELVA ON 9707 3278

Welcome everybody and thank you for joining us today.

Apologies: Gwen McInness

Gwen is still in hospital after breaking her ankle and it is just a long process because **she has CIDP and diabetes. She is really good and bright as a button** and looking forward to finally getting back in the house.

On a **sad note**, I had a **phone call from Vicki Malcolm to say Peter passed away at the beginning of June.** (Reaction from all who knew him.) **So that is very sad.** He was not at all well for a long time. I had a good talk to Vicki and she is managing quite well.

I have also had a message through **Andrew Kornberg** to say that he will be back at the beginning of **August.** I didn't realize but he has had a **12-month break.** When he arrives back home I will send a message about our Christmas function.

Treasurer's Report:

Being the last quarter of our financial year it has been a quiet quarter but from **July 1 I will be busy banking next year's subscriptions from people.**

Just looking at the last quarter ending 31st March, we have had income totalling \$3227 and of that we had craft sales of **\$283 from Gwen for the dolls and thanks to her ladies and that is totalling us to \$770 for the year.**

I have received last year's **Self Help Program** that I apply for every 2 years and we received \$1500 from the DHHS which is very welcome. For the quarter, a few late subscriptions \$215 and of course **donations flowing very nicely of \$1239 came in with those subscriptions.**

They are very nice figures, which leaves us with a balance of \$12,181 which is where we are at the moment. **We will be looking at a donation this year once the Committee approve a figure and hopefully we will be able to hand it to Andrew personally if he can join us for the end of year luncheon or our Annual General Meeting.**

Thanks to all our members for their generosity. (We say this every quarter.) You are all a generous lot and our donations far, far exceed our small membership fees. We put this to research to try and find some more answers to our problems, so thank you all.

Margaret: I just thought I should mention about our **next meeting as we are having entertainment. He is not really a speaker, but if you would like, please bring your family members or friends as we are having a COMEDIAN, Don Jones, who is being paid for by some Government money that we get and he is very good. We thought that a dose of laughter would be good medicine for everyone. We are looking forward to seeing as many people as possible.**

Now I have the pleasure of welcoming our speaker who is Mr. Rob. McManus from St. Johns' Ambulance Community Transport Service. Rob, you are going to talk to us and you are happy to answer any questions?

Rob: Absolutely. Thank you.

Talk by Mr. Rob McManus from St. Johns Ambulance Community Transport Service.

Hi everyone. Thank you for your time today. I am here today to talk about a new service that **St. John** launched, our **Community Transport Service**. I have a few flyers so I will pass these around so you can have a bit of a look.

This is a low-cost transport service that we launched in November last year. We operate Community Programs across Victoria and we were looking at **a new way to have an impact in the Community. We looked at what St. John was running in other states and around the world** and a lot of states and territories **are running a Community Transport Service** and it was something we were not doing.

We did some market research and spoke to some of the **existing providers** and they were quite **welcoming to us** being able to be a provider as well. They outlined that **they just couldn't meet the need in the community** and there is not a lot of funding around.

We are a pretty good organization with a well-recognized brand and we have the means to purchase new cars and **we have a large volunteer base** as well so we decided to launch the service. As I said **it is a low-cost service** and we set our price at approximately **half the price of a Taxi** and we have **volunteer drivers who transport people** from place to place.

All of **our drivers are First Aid trained**. We have a **First Aid Kit and a defibrillator in the vehicle** and really **there are no requirements to use the service**. There is nothing that will disqualify someone from using the service, as long as they **are able to make their way into the car**. At the moment we **don't have a wheelchair service**. Probably we could do that in the future at some point.

We started in the City of Monash where our headquarters is and we have **expanded across the South East of Melbourne so far** and have a growth program and I am here to talk about that program and open up to questions from all of you.

We take **bookings over the phone and you need to book at least 1 day before your appointment** or visit. A lot of people at the moment are using our service **to go to medical appointment**, to go **shopping** or to go to a social club or to get their hair done, or **really anything they want**. It is designed **for people who are unable to transport themselves** so there are a lot of people who would use this service who don't like getting a taxi or don't like getting public transport as it takes too long or isn't suitable. **A pretty exciting program for us** so far. It gives us an opportunity to meet a lot of people and we get a lot of **good feedback from the customers** we have transported so far.

We are doing about **100 trips a month at the moment** and we **plan to reach 20,000 trips annually** over the next few years. It is an awesome service and we have had very good feedback. **Our goal is for it to be cost neutral**. We are **trying to keep the costs as low as possible** for our customers. **Using volunteer drivers** has been great so far.

If you have any questions I am happy to answer them.

Member: A few months ago, on a Saturday night at between 5 and 6, I rang the **Nurse on Call who told me to go to emergency**. I didn't want to catch a taxi and I have a tram in front of me, so I eventually got there. From what you are saying, **it is not for that but for people who can make an appointment**.

Rob: At the moment we are operating the service from **Monday to Friday and it is from 8am to 5pm** and it is **for pre-planned trips**. If we move to a more dynamic model it changes the way we operate. You get more into a "taxi type" licence and that will push our costs up, so at the moment it is for pre-planned appointments. If you do have a regular appointment or you are going to a social engagement or shopping, really there are no restrictions at all.

Member: **When I was a rehab patient, I had a lot of friends in a similar situation who were unable to drive there and they needed to get from their home to rehab. This would be a good option as you know when your appointment is and you can get some assistance in and out of the car.**

Rob: Perfect. We are using **cars and not vans**. Basically, **our drivers** will come out, pick someone up, then **take them to their destination**. **You don't have to go to 5 stops along the way**. You are **not going to spend an hour in the car when you could spend 10 minutes** for example. That's a great example.

Member: **That probably applies to me. I am not yet cleared to drive so my wife drives me everywhere. If I make a call, how soon can a car come?**

Rob: **We take bookings up to 12 o'clock the day before**. As long as we know **one day in advance** then that is completely fine as long as we have room on the service. **We encourage you to book as soon as possible**, but we take bookings up to 12 on the day before.

Member: **Does it work on the lines of the South Eastern Volunteers?**

Rob: Yes. The South Eastern Volunteers was one of the organizations we spoke to before we launched. **It is really difficult for them to get volunteers.** This is the service they do but they don't do any other things. **We do many other things so we have the opportunity to purchase cars. We have got about two and a half thousand volunteers across Victoria.**

Most of what we do is to provide medical and first aid services to events. This is a new volunteering opportunity for people within our organization. We have got a lot more ability to scale than they do and one of the things they said to us was that they are really struggling.

Member: South Eastern Volunteers you have to **ring about a month before** to book it.

Member: I use South Eastern Volunteers and **they are very cheap and they have a really good personal touch about them.**

Rob: What they have found is that there is not a lot of funding in this area. **We are not funded by either State or Federal funding** to run this program. Some other organizations are able to obtain funding, so **we may look at that at some time**, but **South Eastern Volunteers just can't keep up with demand.** It is really difficult for them.

Member: How far are you going? How far in the South East do you go? Past Berwick?

Rob: We are trying to **service the South East, but there are no limits at this point.** As an example, we are actually **taking someone to the Yarra Valley** at the moment for an appointment they have up there **on a weekly basis.**

In the brochure it outlines the charges. Basically, you can do a one-way trip or a round trip and it is based on the kilometres your trip takes.

Member: When you do a round trip and you have an appointment which may take several hours, **is there a time limit before you have to come back?**

Rob: What we ask is for you to give us **an indication of what time you would like us to collect you.** If you know your appointment usually takes a couple of hours, I would recommend you **allow a little bit of a buffer** just because we may be running late on the day, then **we will pick you up at the designated time.**

Member: Or if you wish them to wait?

Rob: We only have a **limited number of cars. We try to keep the cars moving.** If there are no other bookings then the driver might wait, but we **usually have the driver drop you off**, he will go do another trip, **then they or another driver will pick you up at the designated time.**

Member: You said you don't take wheelchairs but do you take people with walkers?

Rob: Yes, we do. The vehicle we are using has a cage in the back. **We do have some customers who can use a wheelchair or can walk a small distance, so even if you have a wheelchair or a walker or anything like that, it can go in the back.**

Member: If you wanted to become a volunteer what do you have to do?

Rob: We are just **in the process of launching** the opportunity **for people to apply directly to Community Transport.** **At the moment** if they want to join us, we only have one volunteering opportunity or **one volunteering path** and that is to **become** what we call **an operational health service volunteer.** What it looks like in the future and **probably in the next couple of weeks, people**

will be able to apply on line. Then they will come along and we will do an assessment session with them and work out if what we are offering is right for them and if they are right for us as a volunteer.

After that we put them through a First Aid Certificate. All our volunteers have a current Crim Check and a current Working with Children check. Basically, we put people through all that training before inducting them into the service, then we show them the vehicle and they are good to go.

Member: What would happen if you had to take a carer with you or something like that? Say if someone had bad eyesight or you needed a carer with you, would that be double the charge?

Rob: You can bring as many people with you as you want as long as we can fit them in the car.

Member: And there doesn't need to be a medical reason. So, use them as a Taxi.

Rob: Absolutely. I guess what we are trying to do is to create an ability to help people maintain their independence and one of the things we heard when talking to the customers is they hated getting a Taxi. People had a bad experience and the cost is quite high. What we found was once people started using us they continued to use us and we have a lot of people now who are using us for more regular things. It can be for an outing as it doesn't need to be a medical appointment. It can literally be anything at all. We took a gentleman recently to the RSL. Dropped him off for a couple of hours then picked him up later on.

Member: Does it have to be age related? So, there is no age restriction?

Rob: I guess when we launched we thought we might have a particular clientele. The more we have been operating, the more we have realized that is not the case. For example: In Western Australia, St Johns have a service there. They do a lot with the Ophthalmology Hospital for people who go in for an eye operation and might be released the same day or a couple of days later. They do a lot of their work there.

The trip that we do out to the Yarra Valley is with a child that is going to a specialist appointment so he has a carer that goes with him. Yes, no age restrictions.

Member: If you have a day procedure and you want to go home, do you do that?

Rob: Absolutely. You can book a one-way or return trip. The return trip doesn't have to be the same day. So, if you are going in somewhere, you can book it and they will pick you up for the return journey on another day.

Is this the type of service you might be interested in using? Have we hit the mark? Is there something we could do better?

Member: I get a cab into St. Vincent's Private and it costs me \$25 in and \$25 home. I live in East Burwood. It is probably something I would look at using once a month. Several of us go in once a month. Sometimes I go in at 11am and have my infusion. I stay overnight; have another infusion the next day then head home about lunch time. This service would really suit me.

Rob: We are not as dynamic as a taxi. We require a specific time for pick up. As we grow we will possibly have the opportunity to become more dynamic in that regard as we will have more vehicles on the road. It is really reliable when you make the booking of an accurate time.

Member: Do the vehicles have signing?

Rob: One of the feedbacks we have had is that our vehicles looked like an Ambulance and that is not what our customers wanted. With our new vehicle (and vehicles in the future), **we have a magnet on the door which says, "St. John" on both the front doors.** It is not as badged up as an ambulance or Uber. It has **no flashing lights.** We are going **nice and clean.**

We are using **Toyota Prius for a lot of reasons, but two are worth mentioning.** It is a **Hybrid** vehicle, so it keeps running and **keeps costs down and they are quite spacious.** Even the back seats are adjustable with **plenty of room in the back** for walkers, etc., and **they are cheap.**

Member: How many vehicles would you have in this region?

Rob: So far, we only have two on the road. To get to 20,000 trips a year I think we will need 10 or 12 which is not a big deal for us to do, but what we want to do is continue to bring in new volunteer, then more customers and then we will scale up. We are probably at the point where we need to buy a new vehicle. That's okay. But piece by piece. That's why you need to make bookings in advance. We need to get another vehicle very soon. We have only been going since November.

I work for St. John's Ambulance and the part I am responsible for is Event Services. Summer is pretty busy for us and from October to April we are flat out doing events. **Now is a good time of year for us to bring more volunteers on, talk to more people about the service, grow it** and then when it gets to summer again, we will probably be quite busy doing the other things. **My plan is to get this up and running. A bit more stable. More drivers. Get someone in to run the program, then continue to grow.**

We are aiming to be cost neutral. We will probably get there when we are a bit bigger. **We are putting money into new vehicles and IT systems and if we can't get volunteer drivers we are paying people to drive. That is costing us more, so we need to grow our volunteer base more. I'm sure in the end it will work out.**

Eastern and South Eastern Volunteers are funded by government and their prices are cheaper than ours. Hopefully at some point in time there may be something like that for us.

When we launched the service we only had the return trip costs. Then we found some people only required on-way, so we have made the change. It is quite easy for us at the moment to make changes.

Member: Do you advertise in Aged Care Facilities?

Rob: We are talking with the Aged Care Facilities but we are not advertising with them. We have found that most of the time those facilities already have an arrangement in place. I think at some time we will be able to work with them and grow the service. **I am being cautious in growing too much because every time we talk to a councillor or hospital they say we will be overrun, but it hasn't happened to this point.** It is **steady growth** with our number of **trips increasing** month by month by about **20%** which is a **manageable growth** which is good. **Definitely in time** we will set up a more **formal arrangement with Aged Care Facilities** to advertise our service.

Member: I think it sounds fabulous, especially for people ageing. We live in an outer suburb and once we are unable to drive we will have to change our life. We don't particularly want to do that, so this would give people the opportunity to stay in their own homes.

Rob: We hope so. There is not this service enough to meet the demand. I knew nothing about this space 12 months ago and **the more I speak to people the more I realize there is a big gap in what is provided in the community.**

Member: If you go one way on a Monday and back on a Friday that is considered a round trip?

Rob: Yeah. You can go to Europe for the Winter and come back in the Summer. No worries. But you must come home before 5pm between Monday and Friday. (Laughter)

Member: Where is your base?

Rob: We are based in Glen Waverley and that is why we are **concentrating on the East/South East area** but **eventually** we will probably **go into the North and have a base there.** Parking is an issue but we are talking to a hospital to potentially use their car park.

Member: Where do you get your volunteers?

Rob: We are very fortunate as an organization because **we are quite well known.** A lot of people know the name but don't know what we do. We, unlike other volunteer organisations, have more interest than we really need. The part I work in is **Event Health Services. We have about 100 applications from volunteers a month and we progress about 50 of those.** That means that some decide we are not the right organisation for them or we have decided they are not quite right for us at that point.

75% of our volunteers are 35 years old or younger. It is a very different group to what people would imagine for a volunteer organisation. We provide First Aid services to most of the events in Victoria. We provide services to Melbourne Park, Rod Laver Arena, Sydney Myer Music Bowl, a lot of the festivals, so it is not like a free ticket but they get to be part of the event. They are working when they are there but we also provide a lot of training for people. It is really good for people to have on their CV if they want to work in the industry. There is a good sense of social cohesion when part of that group. A lot of opportunities at events and away from events.

It will be really **interesting for us watching a new type of volunteering around community transport.** At the moment **all of our drivers have joined as part of the First Aid medical service, then put their hands up to do community transport as well. Hopefully we can recruit more people to be community transport drivers. We are looking at setting up other programs as well and others may join for different reasons.**

Member: Would you look at using people with their own cars?

Rob: What we are trying to do is really have a consistent service. **We do a lot of first aid training, we sell first aid kits, defibrillators, we run a non-emergency transport business.** The commercial activities of our organisation are quite successful. **We are a not for profit charity, so the idea of earning that money is that we can put it back into programs.** This means we don't have the same challenges as other providers do around purchasing cars. When we want **to purchase a car, we have some money in the bank to do it.** We would get into **tricky territory around whether we reimburse a person,** how that would look. We would **become dependent on that person,** whereas we want to support our customers and make sure we can always provide a service. If we had a service like that where someone was using their own car, then they stopped doing that, what would that mean for our capacity to provide the service.

It is easy for us to purchase the vehicles with a first aid kit in the back, etc. to try and make the experience better for the customers. I think it would be too much to expect that from our

volunteers. **We have a really nice fleet that we can continue to grow. Our fleet is recognisable and even though they don't recognise their driver, they know they are part of the organisation.**

Member: One of my friends needed to do volunteer hours for Centrelink and he became a volunteer driver to fulfil his hours.

Rob: We have a number of people who do that at the moment. We sign their letter off whenever it is required. It works well for them and works well for us.

Member: Do you have to register to be part of the service?

Rob: No, just book over the phone. It is as easy as that. Once you have made your first booking we can duplicate your details when you have another booking. We also take Credit Card over the phone. It is not cash, only Credit Card.

Member: Do you have to have an assessment first?

Rob: No. No assessment. We do ask questions when people first ring in to make sure they are able to use our service. As I said, we don't have a wheelchair-based service and our drivers are not trained for people who require a wheelchair full time. If for example someone has not been appropriate for the service, we will follow up with them after that and say unfortunately it is not going to work. The only one we have had was a lady who was too big to fit into the car.

Doug: Thank you Rob. Applause. I think you have let your credentials speak for themselves. St.John have a good name and you don't have to sell yourselves, you just have to sell your services. That's great.

Thank you very much.

Rob: Thank you for your time.

Disclaimer Information presented in "INformation" the Newsletter of the Inflammatory Neuropathy Support Group of Victoria Inc., is intended for information only and should not be considered as advising or diagnosing or treatment of Guillain-Barre Syndrome, CIDP or any other medical condition. Views expressed in articles are those of the authors and do not necessarily reflect the opinions or Policy of The IN Group.

INFORMATION

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)

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ANNUAL SUBSCRIPTION FOR FINANCIAL YEAR 1-7-2018 TO 30-6-2019

Item	Each	Payable
Annual Subscription	\$15	
(Due 1 July each year)		
GBS Booklet	\$3	
CIDP Booklet	\$3	
After GBS Booklet	\$3	
The Road to Recovery Booklet	\$6	
Boy, Is this Guy Sick Booklet	\$2	
Recipe Book	\$16	
Donation to support Medical Research (Donations of \$2 or more are tax deductible)		
Tick if a receipt is required		
TOTAL Enclosed a cheque/money order (payable to The IN Group)		

Thank you. Please forward this form along with your payment to:

The 'IN' Group, 26 Belmont Rd., GLEN WAVERLEY 3150

	BSB / Account: 063142 / 10006285
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To receive your Newsletter by email sent an email to John@bal.net.au	

AGENDA

2018 ANNUAL GENERAL MEETING

The Inflammatory Neuropathy Support Group of Victoria, Incorporated

BALWYN LIBRARY MEETING ROOM, 2pm on 19/8/17.

1. Confirmation of Minutes of 2017 AGM.
 2. Reports from President and Treasurer
 3. Election of Officers and Members of Committee.
 4. Any special business of which notice has been given.
-

Positions to be filled are: President, Vice-President, Secretary, Treasurer,
Public Officer, Membership/Newsletter Co-ordinator, General Committee Member/s

Nomination form for Committee

Position:

Nominee:

Nominated by:

Seconded by:

Accepted by:

Date:

To be returned to: The Secretary,

The IN Group, 26 Belmont Rd., GLEN WAVERLEY 3150 by 15th August, 2018.

Signature of Nominee: Date:

Please be advised that notice has to be given on any matter to be raised at the Annual General Meeting.