

PARKINSON'S UK FIFE

'KEEPING US TOGETHER' 19

Alex Blair - 1938 – 2021

All members of the Fife Branch of Parkinson's UK were saddened to hear of Alex passing to higher office on 10th May 2021. Alex along with his wife Annabel were responsible for instigating many of the events and activities that we all enjoyed, until the lockdown, and will enjoy again in the near future.



Alex and Annabel - you can't really talk of one without the other in the context of the Fife Branch but in this short reflection I will try and talk of Alex on his own.

For those of you who attended Alex's funeral or watched online, you will have heard, through the celebrant, the love, affection and inspiration that his family appreciated from Alex as the head of the family. In a very similar way the members of the Fife Branch have lost our father figure. Never one for wasting words, when Alex spoke, we all listened and respected his opinion even if it meant changes were needed. One of the Parkinson's staff who does so much in support of the Branch said, on hearing the sad news, "I loved working with Alex - he kept me on my toes in a lovely way". A past member of the committee remembered that if you agreed to do something you could be sure that Alex would nag you until it was done. A member of the senior staff in London remarked "He taught me a lot about Parkinson's and was always a pleasure to spend time with - whatever the question!".

Alex and Annabel were responsible for starting our popular Walking Group. The regular Tai Chi sessions also have the Alex Blair source of origin stamp. I've been told that he was encouraged to try Tai Chi by a swimming friend. At his first session at Woodmill High School Alex opted for the hiding-in-the-back option. More confidence came later when he convinced Annabel and their daughter to join the class. When the public session closed down Alex started the now very popular activity within the Fife Branch portfolio.

Alex lived with Parkinson's for many years but he didn't let it stop him in anything he was doing. Alex tackled anything and everything with a gusto and boundless energy. As a member of the Fife Branch Committee for many years his contribution to the branch in all its forms was immense.



During my time as the Branch Chairman, I have been so grateful to Alex for his advice, ideas and comment and in particular his ready smile. At the end of committee meetings when I went around the table asking for any other business, most people respond, 'no'. However, I always knew that Alex would have something to say; often just a small "pebble to drop in the water" but occasionally something that made "bigger waves".

He was always available to give advice and help to all who needed it and his kindness to all will be greatly missed.

Thank you, Alex, for all that you have given.

John Minhinick Parkinson's UK (Fife Branch) Chairman

Hello Readers

Welcome to 'Keeping Us Together No. 19'. Our thanks go once again to all our contributors.

Since we sent out our last newsletter, our hottest news is that Mark Coxe's poetry book '**Reflections - Poetic Thoughts About Parkinson's, Pandemic and Life**' has been published and has now sold over 250 copies. It looks very classy, contains amazing illustrations by Mr Tom C. Murray QBE and sixty-six of Mark's best poems as only Mark can write.

Paul Mayhew-Archer, co-writer of 'The Vicar of Dibley' wrote, 'I grinned all the way through this terrific collection.'

If you would like a copy, please contact Mark. The cost is £10 plus £3.50 post and packaging if required. All money raised will go to Parkinson's UK Scotland Active Appeal and our own Fife Branch.



Charles Small - 01592 713824 cjsmall12@tiscali.co.uk Mark Coxe – 07913 207057 markcoxe@blueyonder.co.uk

Coffee and Chat Group

There is no shortage of topics to discuss at our Coffee and Chat sessions but somehow, we always return to the subject of holidays! (I wonder why?) From coach trips, hotel stays and glamping at home to beach holidays in Lanzarote and Cyprus.

Several of our members had recently bought new cars or are thinking about doing so. Elizabeth was able to give a fairly detailed explanation of how a hybrid car worked which impressed us all (well certainly me!) Sally made us laugh by saying that it was the first time she and Alex had agreed when choosing their new car.

We were excited about the recent delivery to our homes of Mark's Poetry Book. We agreed that it was a lovely book and perfect for dipping into.

We were looking forward to all the shops opening up again, especially clothes shops. And whilst on the subject of clothing, clever Jenny makes her own pink, silk shorts to wear in bed as they apparently help her to turn over. I'm sure she would be very happy to take orders!

At our next meeting on Wednesday 2nd June at 11am, we may well be talking about getting back together in-person in the not-too-distant future! Look forward to seeing you all then.

Briar Richardson



Haiku Hangout

俳句たまり場

Here are a few more Haiku verses that we have received. Thank you, Matthew and David.

Masks, hand gel, long queues,
Zoom meetings, walks and box sets.
A life in lockdown.

Matthew Dodd

Trees burst into leaf,
Sunbeams gently warm my face,
Spring is here at last.

Matthew Dodd

Plus

David Allan's Parkinson's Haikus

Micrographia -
My erstwhile proud penmanship
Now illegible

After two hours' sleep
Two a.m. wide awake and
Another day starts

Repeating myself
Has become a new normal
Life with Parkinson's

Sialorrhea is
A sophisticated word
Which just means drooling

**WALKING GROUP ZOOM MEETING –
FRIDAYS 30TH APRIL AND 14TH MAY 2021**

We were on our travels again at our recent meetings and on the 30th April Bob took us on a most enjoyable trip to the Isles of Lewis and Harris, illustrating his talk with photographs of the wild mountains, beautiful white beaches, rugged coastlines and the impressive standing stones at Calanais on The Isle of Lewis.



At our next meeting on 14th May we flew off to Kenya in Africa and were treated to a very interesting, illustrated talk by Jane Richard who, in 1985, had spent a year teaching on an exchange programme in a school on the outskirts of Nairobi. The children at the school had little in the way of resources, often having to share textbooks between large groups and making the most of recycling paper bags for drawing material! The children were very inventive in recycling containers and materials to make toys such as footballs and racing cars for an annual competition. It was a most enjoyable talk and made us appreciate the resources available to our children.



As you will know from the last Newsletter we have a tentative date for a first post-pandemic walk on Friday 18th June at Pittencrieff Park in Dunfermline. We will keep you posted about the arrangements and send out full details prior to the walk; if you want any further information please get in touch with Bob and Frances Copeland or Elizabeth Tait. The boots are not quite out yet but have been moved from the back of the cupboard to the front in anticipation!



Elizabeth Tait

Joining codes and Passwords can be found in the Branch Schedule email.

Janet's Morning Stretch 'Rise and Shine'
1015am Monday

Get Together 'Talk For Scotland'
11am Monday

Eric's Tai Chi 'Marshalling the Oriental Art'
11am Tuesday

Camera Club 'No Negatives Here'
10am Wednesday 9th & 23rd.

Coffee & Chat 'More Milk Vicar?'
11.00am Wednesday 2nd 16th & 30th.

Quiz Evening 'Universally Challenged'
7:30pm Wednesday 9th & 23rd.

Alex's Dance/Exercise & Chat 'Five-Six-Seven-Eight'. 11:15am Thursday

Walking Group 'Another Step Forward'
10:30am Friday 11th & 25th.

Meri's Sing-along 'Singing Together – Virtually'
09:45am Friday 4th & 18th.

Spring Wordsearch

Spring, April, May, Daffodil, Bird, Nest Sun, Tulips, Birdsong, Buds, Lambs, Hail, Snowdrops, Showers.

B	D	S	N	O	W	P	A	D	S
I	A	C	H	D	R	O	P	S	U
R	F	S	H	O	W	E	R	S	N
D	F	P	B	T	U	L	I	P	S
S	O	R	I	H	A	I	L	B	O
O	D	I	R	G	D	V	K	U	M
N	I	N	D	N	E	S	T	D	A
G	L	G	F	L	A	M	B	S	Y

Richard Wemyss

Our Guest Speaker

At our Get-Together Zoom Meeting on Monday 19th April was Mr Richard Wemyss from Cellardyke,

who joined us to tell us about an amazingly exciting project he was heading up.

Richard has had a passionate interest in fishing boats, the fishing industry, fisher families – in fact all things fishing, for as long as he can remember and way before he became curator of the Anstruther Fisheries Museum for a few years in the 1970s. Over the years, he has been inspired to produce wonderful paintings, to compose many musical works and create several dramatic pieces/events - a man of many, many parts indeed!

Richard's latest project centres round a fishing boat built in Cellardyke and launched on 11th June in 1937 called the 'Manx Beauty'.



As Richard already knew about the boat and had started to work on a musical show about her, he was keen to acquire it.



Unfortunately, the price was too high and it was another two years before 'The Manx Beauty' came into his possession. We were all amazed as Richard described everything that was involved in bringing this important fishing boat home to Cellardyke. We were also amazed at the cost of achieving this!

However, the project had evolved in Richard's mind and had become a full-on Community Project which only the bravest would take on. Having managed to bring the 'Manx Beauty' back to Cellardyke it could now be restored to its former glory. This would involve community members of all ages. Opportunities for volunteers to learn new skills and inter-generational skill sharing would be created and developed.



She was commissioned by the Manx Government to encourage young Manxmen back to the fishing industry after its decline. Five Fishermen were encouraged to skipper the boats and show the Manxmen the ropes.

She started her long career working in the Irish Sea and she also saw the stormy waters off Tobermory, plying her trade from Conway in North Wales, Padstow, Cornwall, and later ended up in Birkenhead and was put up for sale.



Richard then told us how the music side of the project had been developing with new musicians and new links with the Royal Conservatoire of Scotland established. The project would now be linking and working with schools, young musicians

in The Isle of Man, Fraserburgh, Shetland and the East Neuk of Fife as well as a distinguished group of professionals including Margaret Robertson MBE, Rachel Gray, Isla Callister, David Behrens and Martin Malone. Opportunities would be provided for performers, technical and support staff to create, build, write, compose, play and perform in workshops leading up to a brand new dramatic, musical, staged performance. In fact, Richard would welcome support from anyone interested in the history of fishing and how it can inspire communities today.

Richard held us in the palm of his for far longer than he expected and was good enough to then answer questions about his presentation. Our members were totally engrossed in the story and were already looking forward to hearing about the progress of the project later in the year.

Thank you, Richard, for sharing your story with us in such an interesting and captivating way. It was great to share your enthusiasm and vision and we wish you well with the project.



**GET IN TOUCH with
Parkinson's UK
0808 800 0303**

**IMPORTANT – IMPORTANT – IMPORTANT
HAVE YOU RETURNED YOUR BRANCH
QUESTIONNAIRE YET?**

Recently, our Committee sent out an important Questionnaire to all our PUK/Branch Members about the future of our Branch, as we start to come out of Covid 19 restrictions. Once analysed the answers will help to inform the Committee on how to proceed, taking everyone's views into account. The more replies returned, the better the information will be, so **PLEASE, PLEASE, complete your questionnaire and return it to John Minhinick a.s.a.p.** If you have mislaid your questionnaire, please contact Charles Small 01592 713824 and he will either send out another one or fill one in on the phone for you, if that is easier.

This is a great chance for our Committee and our Branch Members to design our activities to meet the needs of our membership in 2021 and beyond. The Committee want to get things right but can only really do this if members share their views and ideas.

Thank you to everyone who has already returned their questionnaire and I look forward to reporting a flood of replies in the next week or so. **Act now and make your ideas count.** Thank you very much.

IMPORTANT – IMPORTANT – IMPORTANT

DONATIONS TO OUR BRANCH - Alex Rodger

Our Fife Branch of Parkinson's UK is always very grateful to receive donations from members, their families and friends and from individuals and groups who wish to raise money for a local charity. We are aware that these donations are given after times of celebration and enjoyment but that sometimes they are gifted after times of sadness. Thanks to the latest donors.

Alan Chapman, Ken & Diane Dunbar, Christine Descouts and Annette Fitzsimmons

Donations to our 'Just Giving' page

Annette Rae, Julie Richardson and from Pamela Carlstedt in memory of her beloved uncle, John Kersley

If you or someone you know is thinking about fundraising, remember that our Fife Branch has its own 'Just Giving' page, where you can increase your donation with Gift Aid. You can find the link on our own web site, fifeparkinsons.org



Thank You

I would like to thank everyone who sent letters, cards, emails and messages to me following the loss of my husband, Alex. Your words meant a great deal to my family and I. Unfortunately, I don't have everyone's contact addresses but I hope that this message will reach you all.

Thank you, Annabel Blair

Stunning Saffron Sunrise

Thank you, Matthew Dodd for sending in a spectacular photograph of a sunrise behind Arthur's Seat and Edinburgh Castle taken from his flat window. Matthew says that seeing the sunrise is one advantage of his young daughter, Flora, waking mum and dad up early!



Wordsearch Solution

B	D	S	N	O	W	P	A	D	S
I	A	C	H	D	R	O	P	S	U
R	F	S	H	O	W	E	R	S	N
D	F	P	B	T	U	L	I	P	S
S	O	R	I	H	A	I	L	B	O
O	D	I	R	G	D	V	K	U	M
N	I	N	D	N	E	S	T	D	A
G	L	G	F	L	A	M	B	S	Y

Eyemouth Tart

Recipe from Diane Dunbar

Ingredients

50g / 2oz walnuts
50g / 2oz currants
50g / 2oz coconut
50g / 2oz cherries
50g / 2oz raisins
75g / 3oz sugar
1 egg (beaten)

225g / 8oz icing sugar

225g / 8oz shortcrust pastry

25g / 1oz melted butter (melted)

Method

Roll out the pastry and line a Swiss roll tin.

Mix the dry ingredients together in a bowl.

Add beaten egg and melted butter.

Spread the mixture over the pastry.

Bake in oven (375 F, Gas 5) until golden brown

Mix icing sugar with very little water

Ice while hot

Leave to cool, cut into portions.



Thanks, Diane for another VERY delicious if not slimming recipe!

Featuring in the next edition Briar Richardson's Rhubarb Ginger Crunch

Modifying your mail preferences

Does your household receive duplicate mailings from Parkinson's UK? If so, please contact our Supporter Care team and let them know your preferences, saving both money and trees! Contact the team on 0800 138 6593 or supportercare@parkinsons.org.uk and they will make the necessary changes.

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Meet Our Branch Research Champion

We featured in our Keeping In Touch Newsletters 14 and 15, three special Zoom events to be held in January, February and March 2021 titled Parkinson's and Technology; 1. Managing the Parkinson's Condition, 2. Managing Daily Life with Parkinson's and 3. Towards a Personalised and Optimal Treatment. The events jointly organised by DRIG, SIGP@T and WPC attracted 324 individual participants with three out of five people attending at least two events. Our own Branch Research Champion, Werner Remmele was a key player in bringing this amazing project our screens and I asked Werner to share with us his personal story and also about his connection to the World Parkinson Congress 2022.

Digital Parkinson's - My Personal Story – Werner Remmele

How it all started



I was diagnosed with Parkinson's in 2009 and I did not know much about the illness then. Several years later not much had changed when I got the opportunity to participate in the 2013 WPC (World Parkinson Congress) in Montreal.

The sheer size of the event with 3500 participants, many of them PwP at all states of the illness was impressive, but what struck me even more was the spirit of optimism and the determination to take on the fight.

Attending this event became my life changer. It took only these four days in Canada to show me every facet of Parkinson's: its cruel consequences but surprisingly also many positive aspects and above all, the great community of people all seemingly dedicated to join me on my own journey with Parkinson's.

And I met most remarkable people on the way.

From now on my journey was directed towards the goal to contribute to the fight against the illness.

Reflection – the SIGP@T events

My personal background in computer science and mathematics influenced the topics I chose: I am very much interested in technology itself and its possibilities to support living with Parkinson's.

With continuously increasing 'intelligence' of devices, a wide field of possibilities for novel use cases opened up: it was now no longer just about tools to make life easier, but also to control the disease and, beyond that, to create the best environment to treat the disease. The three events in Jan, Feb and March 2021 reflect these increasing capabilities: intelligent solutions are enablers for managing the illness, the daily life and providing data for a personal, optimal treatment.

The next steps

We are still a tiny group but pursue high aims: We want to become a knowledge and information hub between Parkinson's patients and R&D and we will play an active role to be able to use the outcome measures of digital tools in the diagnose and treatment of Parkinson's. To do so we need to widen our activities and become drivers especially in the field of standardisation of symptom interpretation; there needs to be a standard way to describe symptoms and their severity to use them cross applications. Without that every attempt to use digital tools will be isolated, stand-alone, and therefore not contribute to a widely accepted strategy to deal with the illness.

This sounds very ambitious, but bringing together the patients, who are the prime experts of the needs – or in technical terms you may say the ‘requirements’ – and the knowledge about possibilities, we should be in an excellent position to accomplish that.

Connection to WPC – Closing the Circle

I did not have this global concept in my mind after the 2013 WPC, but I certainly focussed from being ‘patiently waiting’ to becoming ‘impatiently active’, now driven by a goal. And I wanted to experience this ‘we can do it’ feeling of the 2013 WPC again. Unfortunately, I was not able to participate in the WPCs in Portland (2016) or Kyoto (2019) but was determined to participate in the 2022 WPC in Barcelona, when – even better – I was offered to become an ambassador for the congress.

This development was a boost, as I am now able to use resources, I would not be able to address otherwise. It also stretched the reach of our ideas to become active contributors to the congress. We are determined to give technology the place it deserves, find people to submit papers and have our own booth at the congress.



Of course, there is much to be done to make all this happen, but we’re not frightened to do so.

We will be inviting you soon to participate in a project of a completely different kind: We hope to create a piece of art that will be unveiled and subsequently sold in an auction at the Barcelona event. Why do I mention this here? YOU can and should participate. It will be easy: it will just requires taking a picture and – optional – writing a statement or a short story. And the best news is that the money raised will be donated to a research project in the field of intelligent solutions. All necessary information will soon be published on our website. We will keep you informed.

What’s left to do

Being a tiny group of people with big plans we can use any help we can get even if you will just occasionally inform us about interesting news – just let us know.

... and finally

I want to thank everyone having contributed over the past months:



- The team that planned and organised the events – Brendan, Jo, John, Liz and Marc, to name the ones who took on the biggest workload
- The eleven outstanding speakers
- Paul Mayhew-Archer and Rory Cellan Jones for their personal contributions
- DRIG and Parkinson’s UK for support and Communication Infrastructure



And last but not least you all for your interest.

Thank you, Werner for providing us with such a comprehensive update on your own story and the future WPC events.