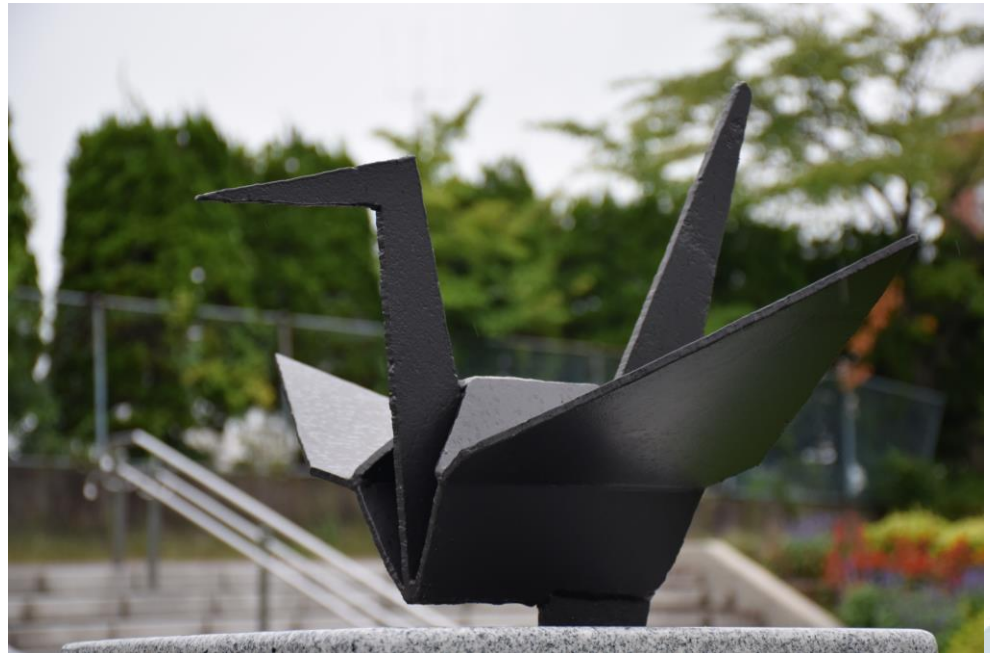


World Parkinson Congress



The Crane - a symbol of hope and healing

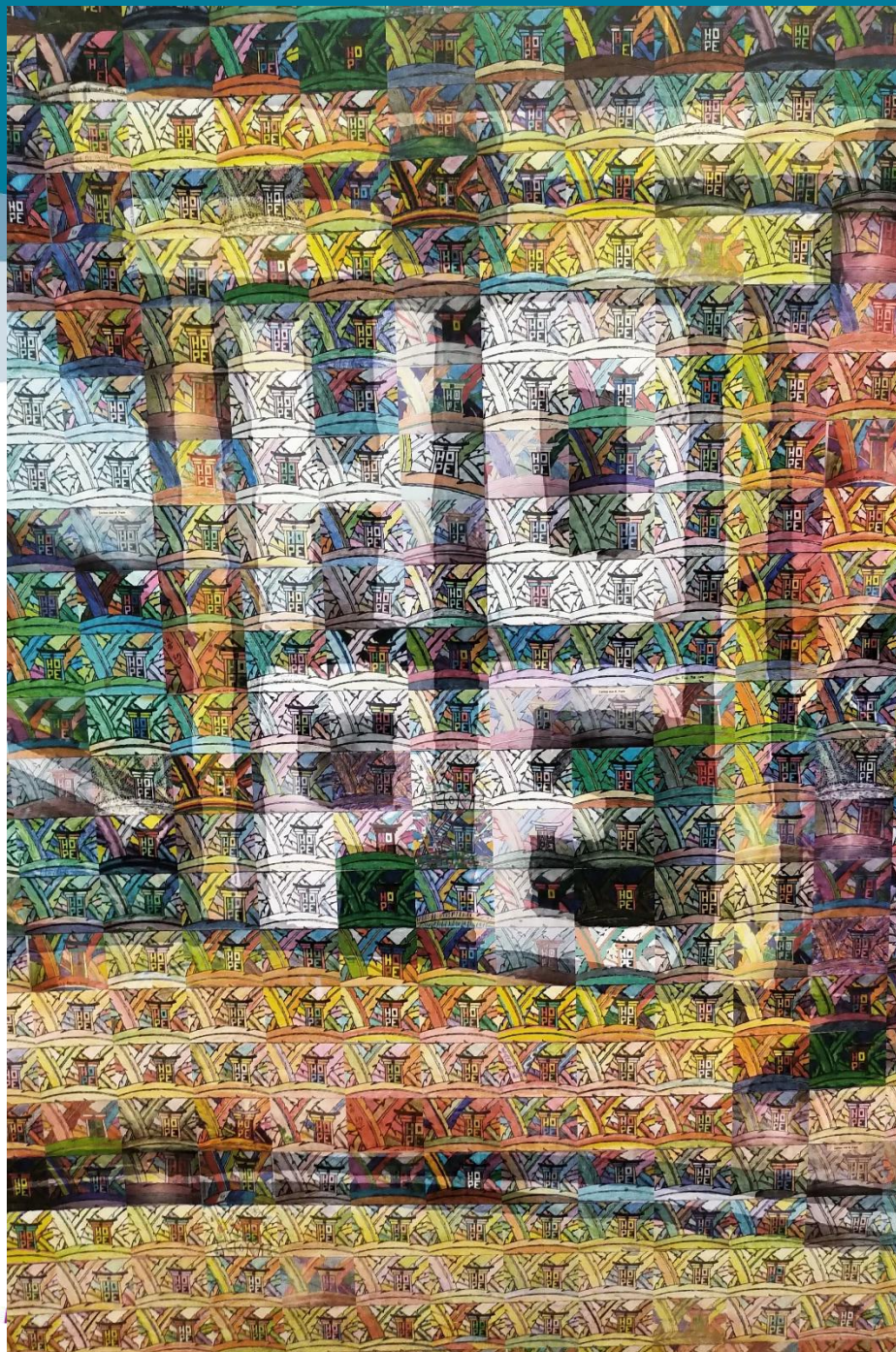


The Story of Sadako Sasaki



Soaring With Hope





Wellness Way Plus

- Wellness Way
- Pre-Congress Course IV: Activism, and roles patients play
- Roundtable: Living well with Parkinson's: What's the secret?

Wellness Way Plus

- Exhibitors area
- Wearing “Wearable” devices
- Clinical Research Village

Wearables

- To improve diagnosis of PD
- To improve monitoring of PD
- To encourage increased activity or track compliance with an exercise program
- To improve clinical trial data

Examples of Wearables

- Improved monitoring of PD
 - Personal Kinetigraph™ (PKG™) - informs decision to change medications.
- Microsoft prototype of a watch under development
 - Emma's watch -vibrating motors to dampen tremor.

Leadership Forum

- Reaching the Newly Diagnosed
- Finding the Underserved
- Starting a PD Program and Empowering Those Who Want to
- Increasing Engagement with Support Groups
- The Role of Industry

Pre-Congress – Advances in Research

- DBS
 - Rechargeable lasts 15 years; 1x week
 - Flexible, more precise current delivery systems & avoid unwanted side effects
- Infusion therapies
 - “Accordion” capsules –extended release
 - Inhaled
 - Epi-pen
 - Pump patch
 - Apomorphine

Pre-Congress – Advances in Research

- Transcranial Stimulation
- Vestibular Stimulation
- Gene Therapy
- Immunotherapy
- Focussed Ultrasound

iPS Cells & Medical Application

- **Dr. Shinya Yamanaka**, Japan –2012 Nobel Laureate in Physiology Medicine.
- Reprogramming mature cells to become pluripotent including neurons.
- Clinical trials with human subjects for macular degeneration and immunotherapy work in cancer with animal research.
- New trial with Parkinson's

Stem Cells – the Takahashi's

- Trial - dopaminergic progenitors from pluripotent stem (iPS) cells and inject them into the brain.
- Monkey models significant improvement after 2 years
- First trial, retinal cells to replace eye tissue damaged by age-related macular degeneration in 2014.
- 2019 conditional approval for ischemic heart disease.
- 2018 Parkinson's.
- Seven patients; follow for 2 years.
- The first patient injected on one side of the brain November (2018.)

Definition of advanced Parkinson's disease: Delphi consensus

A Delphi panel (n=20) evaluating clinical indicators for advancing Parkinson's disease determined that the most important clinical indicators of motor symptoms were: moderate level of troublesome motor fluctuations, ≥ 2 hours of the day with off-symptoms, ≥ 1 hour of the day with troublesome dyskinesia, moderate level of dyskinesia, troublesome dysphagia and ≥ 5 times oral levodopa doses per day.

5  times oral
levodopa
use per day

2  hours of
the day with
off-symptoms

1  hour of the day
with troublesome
dyskinesia

abbvie
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Adams et al. J Clin Med Res Open 2010; 34:2003-2013

Talk to your doctor about
your condition or treatment

Empowering people with advanced PD

- realities of progression
- medications dosages cannot always be increased and achieve symptom control.
- learning about options –
 - DBS,
 - pump therapies
 - intestinal (Duodopa)
 - Skin (apomorphine infusion).
 - oral meds up to 8 to 10 times per day

Why Personalized Medicine?

PD not just one disease. Broad clinical subtypes :

- Mainly motor; slow progression
- Intermediate
- Diffuse or malignant; more cognitive impairment, balance issues, random behavior disorders.

Why Personalized Medicine?

- Co-pathology with non-synuclein.
- Substantial variation - other factors?
- Contribution of vascular disease
- Multiple cellular processes
- Complex puzzle - one size does not fit all.
- Breast cancer work as a potential model.

Personalized Medicine - Benefits?

- Diagnose more accurately
- Optimal therapies; target medicines and dosages precisely
- Increase safety; reduce adverse drug reactions
- Detect onset of disease earlier
- Shift from reaction to prevention
- Increase efficiency and improve quality

Anxiety

- Prominent non-motor symptom
- Global prevalence 31%
- Occurrence significantly higher than in general population.
- Detrimentally impacts activities of daily living even more so than motor symptoms.
- Those with anxiety experience 50% poorer quality of life, 5 times more complications from PD therapy, and 10 times greater disability.

Nonpharmacological Interventions

- Meditation and relaxation exercises
- Schedule worry time
- Act the opposite
- Healthy sleep habits
- Rethink the big picture -catch the negative thought, press pause, rewind, replay
- Cognitive Restructuring
- Simplified restructuring - Revising a linear negative thought into a broader positive one
- Conducting self assessment questions on worry, fear, outlook, situations that bring you anxiety
- Seek resources

PD Outside the Brain

Why Intestines and PD?

- 100 Trillion bacteria in gut along with toxins
- Large surface area
- Barrier, immune functions
- 100 million nerve cells
- Direct connection to CNS (spinal cord)
- Patients with inflammatory bowel disease have a higher risk of PD. However, treat the IBD and lower the risk.
- One day be possible to use colonic tissue biopsy to predict who will develop motor PD.

Live, Not Just Survive, with Parkinson's Disease

We were born to play, move and live a full life

Suzi Diggle, Ph.D., GNP, ANP, B-C Nurse Educator/Assistant Professor
Graduate of Edmond J. Safra Parkinson's Foundation Program

Introduction

In order to live your life to the fullest you must be aware, educated and active. Progression with Parkinson's disease (PD) is slow and most people can live their normal, expected life span. This poster will highlight some PD signs and symptoms and education for maintaining or increasing independence, safety and quality of life.



Signs and Symptoms

- Gastrointestinal issues (i.e., constipation, drooling, GERD, weight loss)
- Swallowing and speech issues
- Other communication issues (i.e., writing size)
- Sleep issues (i.e., restless leg syndrome, REM behavior disorder, early wakening, nightmares, daytime sleepiness)
- Movement issues (i.e., freezing and falling)
- Orthostatic blood pressure (increased falls)
- Cognitive changes (rule out other causes)
- Impulsiveness
- Depression and anxiety
- Sexual issues
- Skin changes

Increasing Independence, Safety and Quality of Life

- Commit to mobility** - daily walking, swimming, cycling, housework, gardening...
- Stay connected** - join groups of others with PD for support, and also join groups of people that do things that you enjoy who hold you accountable for showing up

Resources

- Parkinson's Disease Foundation toll-free National Helpline 800.457.6676 or info@pdf.org
- American Parkinson's Disease Association (APDA) 800.651.8466
- The Michael J. Fox Foundation for Parkinson's Research: www.michaelfox.org

- Home Safety** - prevent falls in the home by removing trip hazards and keeping multiple phones within reach
- Driving Safety** - consult with the experts, accept your limitations, and enjoy the ride as a passenger
- Travel Safety** - plan ahead and call the Parkinson's helpline to map out potential caregivers along the route just in case 800.565.3000



Ways to Improve Health Visits and How to Prepare for Visits

Include the following PD specialists:

- Nursing
- Movement Disorder Doctors
- Physical Therapy
- Occupational Therapy
- Speech Therapy
- Counseling

Healthy Living

- Good hydration
- Diet: Mediterranean
- Consider amount of protein and timing
- How about carbs?
- Medication to avoid and those that are safe to take with PD
- Communication issues and ways to improve
- Skin care

References

- Parkinson's Disease Foundation. (2015) Q&A Seventh Ed. 5-52.
- American Parkinson Disease Association (2018). Medications to be avoided or used with caution in Parkinson's disease. www.apdaparkinson.org/wp-content/uploads/2018/05/APDA-Meds_to_Avoid.pdf

P43.07

The patient at the centre of a multi-disciplinary team approach to Parkinson's care: a personal perspective

Janet Niven, diagnosed with PD in 2014
Local Branch Volunteer & member of Excellence Network, Parkinson's UK

Angus is a rural county in the north east of Scotland and the NHS Parkinson's clinics are based in three geographical locations. The teams involved in the patients' care are multi-disciplinary with the patients being very much at the heart of it.

Non-motor symptom questionnaire

Question	Yes	No
1. Do you have any of the following symptoms?		
2. How often do you experience these symptoms?		
3. How much do these symptoms affect your daily life?		
4. Have you ever been told you have any of these conditions?		
5. Have you ever been treated for any of these conditions?		
6. Have you ever been advised to stop taking any of these medicines?		
7. Have you ever been advised to start taking any of these medicines?		
8. Have you ever been advised to change the dose of any of these medicines?		
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100. Have you ever been advised to start taking any of these medicines?		

Physiotherapist:
Assesses walking, gait, balance & posture, advises on e.g. exercise (types and frequency); how to prevent falls

Occupational Therapist:
Discusses problems with day to day activities in the home and with going outside the home, assesses writing

Nurse / H.C.A.:
Measures height, weight & blood pressure for postural hypotension

Referrals:
To other clinics/services as required e.g. speech & language therapy, falls, continence, exercise



Parkinson's Consultant:
Assesses for tremor, rigidity and bradykinesia, discusses any changes and concerns, discusses medication

Parkinson's Nurse Specialist:
Discusses NMS questionnaire, tests cognitive function, checks results of postural hypotension tests

Team meeting

Unified Parkinson's Disease Rating Score (U.P.D.R.S.)

Problems from reviews:
Should this happen, the PD nurse can be contacted. Appointments can be arranged as required with the team or referrals made to other services

Patient Follow up Letter:
Parkinson's Nurse summarises the findings of the team and also any medication changes, referrals or advice. G.P. sent a copy

My Personal Perspective

I have found the MDT annual review clinic so beneficial. I feel the team is really interested in me as a person & how PD affects all aspects of my life. I am encouraged to ask any questions & I feel very involved in decisions about my treatment and care. This "one stop" approach allows all the team to assess me on the same day. I am a member of the Excellence Network in Scotland and I would love to encourage more clinics to take up this approach.

"It is a huge help to know you are always there to listen & point in the right direction"
Carer

"I was reassured by the consultant care he received over 15 years & could contact them when necessary"
Carer

"They know me as an individual and have a holistic approach to my care"
Patient

"Management of people with Parkinson's is very complex. It needs involvement from, and communication between, so many different professionals. It's great for them all to see the patient in one clinic and we can have a MDT discussion at the end. Patients and carers all talk to each other the same way. It's a real buzz about it."
Dr. James Shaw Consultant

Some quotes about the clinic

Acknowledgements

I would like to thank the wonderful team at Whitehill H.G.O.C. led by Dr. James Shaw (Consultant Geriatrician) with Linda Patterson (Parkinson's Nurse Specialist), Leigh Gray (Physiotherapist), Lynne Houston (Occupational Therapist), all the nurses in the unit, Brenda Gifford (Secretary), & Eva Vahelainen (Volunteer) for the fantastic care I have received over the past 5 years. They have been so supportive on my Parkinson's journey and in including the patient.

Thanks also to Mary Ebbens (Exercise Improvement Advisor, Scotland, Parkinson's UK) for welcoming me into the Excellence Network and for all her help & encouragement.



Some of the BC Attendees











