The Cure Parkinson's Trust (CPT) celebrates the life of its champion!

The Cure Parkinson's Trust was joined by friends and family at Merchant Taylors' Hall in London on 12th September to celebrate the life and achievements of charity President and Co-founder Tom Isaacs who very sadly died on 31st May 2017. The evening included tributes from Tom's wife Lyndsey, Parkinson's advocates and friends Bryn Williams and Vicki Dillon and The Right Reverend Richard Chartres. There were musical tributes from friend and fellow Parkinson's advocate David Sangster, singer to the stars Cole Page and The Thomas White Singers from Merchant Taylors' School.

Help us deliver Tom's Vision

CPT’s focus for the next five years is to ensure that we develop more trials into potential cures for Parkinson's, by securing funding for drugs prioritised by our international Linked Clinical Trials (LCT) Committee chaired by Professor Patrik Brundin - an initiative that Tom was passionate about. He firmly believed this programme would one day result in treatments to slow, stop or even reverse Parkinson's. We are particularly proud that our LCT initiative has developed into a global programme which already has seven trials underway or completed. By taking drugs that are used in other disease areas and testing them in Parkinson's, we aim to find treatments that will make an impact on people's lives as soon as possible.

However, our committees are prioritising drugs for trial faster than we can secure funding. We have a number of studies that could start very soon. We need your help to fund these trials.

We would like to thank everyone who joined us in celebration and in looking to the future #TomsVision. To see the photographs and read more about the event go to www.cureparkinsons.org.uk/celebrating-tom

Please support our programme of innovative clinical trials

If you would like to make a donation, you can do this easily by:
1. Using the enclosed envelope
2. Donating online at www.cureparkinsons.org.uk/lctappeal
3. Contacting a member of CPT’s Fundraising team on 020 7487 3892

CPT EVENTS DIARY

The Grouse and Grape Luncheon
Spencer House, London
10th October
www.cureparkinsons.org.uk/grouseandgrape

The Tom Isaacs Charity Golf Day
Denham Golf Club, Bucks
19th October
SOLD OUT

Comedy Quiz Night
Gibson Hall, London
1st November
www.cureparkinsons.org.uk/comedy

Research Update Patient Meeting
Deloitte, London
7th November
www.cureparkinsons.org.uk/research-update-patient-meeting

The Virgin Money London Marathon
22nd April 2018
To apply for a place: www.cureparkinsons.org.uk/vmlm18

The Gulls' Eggs Luncheon
Merchant Taylors' Hall, London
15th May 2018
www.cureparkinsons.org.uk/gullseggs

Open Garden
Petersham Lodge, Richmond
20th May 2018
Please keep an eye on the website for more details

Vitality London 10,000
28th May 2018
To apply for a place: www.cureparkinsons.org.uk/vitality-10k
Research Update

Diabetes drug hints at capability to slow Parkinson’s

For the last 8 years, CPT has invested in developing drugs that are used to treat type II diabetes called GLP-1 agonists as potential disease-modifying treatments for Parkinson’s. With Professor Tom Foltynie we supported the first study of exenatide in people with Parkinson’s that provided the pivotal groundwork for the recent Bydureon (a weekly version of the same drug) Trial, the results of which were published in The Lancet in August. The objective of the study was to measure whether Bydureon had an effect on the movement (motor) symptoms of people with Parkinson’s when not taking their regular medication, and results showed clear benefit (as measured by the MDS-UPDRS scale). This benefit persisted 12 weeks after stopping the Bydureon injections. The trial also indicated that the drug was safe and generally well tolerated.

CPT is now involved in helping design a larger study to evaluate whether Bydureon/exenatide actually slows disease progression. The results were in line with the earlier, smaller CPT-funded clinical trial in which participants also showed improvements in motor symptoms.

Dr Richard Wyse, CPT’s Director of Research & Development says.

“Our mission to slow, stop and reverse the progression of Parkinson’s, and these pioneering findings, exemplify CPT's innovative strategy. Bydureon was prioritised by our International Linked Clinical Trials (LCT) Committee in 2012 along with two other GLP-1 agonists, Liraglutide and Lixisenatide, both of which are now part of CPT funded clinical trials. Other diabetes treatments such as MSDC-0160 also remain of huge interest”

CPT’s International Linked Clinical Trials Programme:

At the end of September, CPT and the Van Andel Research Institute (VARI) hosted the 6th annual LCT meeting, at the Van Andel Institute in Grand Rapids, Michigan. Once again the committee evaluated and prioritised more than 20 drugs each of which show the biochemical potential to slow down, stop or even reverse Parkinson’s. With seven trials up and running, this programme of trials is going from strength to strength and now it is our job to create trials for this year’s candidate drugs.

In April the Garvan Institute announced its intention to coordinate clinical trials in Australia by building a consortium of clinical researchers, and implementing the drug ideas presented to the LCT committee, supported by funding from Australia. This work is also now getting underway and we hope to see a number of LCT trials take place in Australia in the near future.

To find out more about our LCT initiative visit www.cureparkinsons.org.uk/trials-repurposed-drugs

CPT’s LCT Committee chaired by Professor Patrik Brundin (above) meet for an annual meeting to prioritise potential treatments for Parkinson’s

Join us at our next Patient Research Update Meeting

You can hear more about diabetes treatments and if they could slow or even stop Parkinson’s progression at our next Patient Research Update Meeting on 7th November at the offices of Deloitte in London.

Our research meetings are always very popular so to find out more and book your free place now, please visit www.cureparkinsons.org.uk/Event/research-update-patient-meeting

To keep up-to-date with all our research news, please go to www.cureparkinsons.org.uk/News

The Cure Parkinson’s Trust is proud to be a member of the Association of Medical Research Charities

amrc

ASSOCIATION OF MEDICAL RESEARCH CHARITIES
Advocates for Parkinson’s

Rallying to the Challenge 2017
This year’s *Rallying to the Challenge* meeting took place on 27th and 28th September and was once again hosted by the *Van Andel Research Institute (VARI)* in Grand Rapids, Michigan, US. Over 300 people with Parkinson’s, researchers, clinicians and other advocates from around the world attended this annual patient-led meeting in parallel with the *Grand Challenges in Parkinson’s* scientific conference.

This year’s event focused on exploring access to medications that have not been licensed yet following positive clinical trials in Parkinson’s. Each year CPT develops a survey for the Rallying meeting and this year we explored perceptions of risk and whether it changes with the progression of Parkinson’s, as well as comparing perspectives of healthcare professionals with people with Parkinson’s (PwPs). Over 300 people responded to the survey and the results formed the basis of a presentation by CPT’s Leah Mursaleen and Parkinson’s Advocate Soania Mathur, MD.

We asked what should be considered before making a decision to change treatment or take part in research. This prompted discussion in the focus groups about the potential development of a simple risk evaluation tool to aid decision making. Read more about the survey results and Rallying 2017 at [www.cureparkinsons.org.uk/rallying-2017](http://www.cureparkinsons.org.uk/rallying-2017)

CPT reveals prototype website that will allow people with Parkinson’s to better impact research

Parkinson’s Movement, created by people living with Parkinson’s, is transforming to ensure it can create maximum impact on research. The prototype site was revealed at Rallying 2017. Feedback is being incorporated and the site is now entering its test phase and will be available early in 2018.

We look forward to sharing more details about this exciting project early next year. Thank you to The October Club for enabling this exciting project. If you would like to sign up to receive news about the work of Parkinson’s Movement email julia@cureparkinsons.org.uk

The Tom Isaacs Award
One of the highlights of the *Rallying to the Challenge* meeting was the presentation of the inaugural *Tom Isaacs Award* in honour of CPT’s late co-founder Tom Isaacs, who was described by VARI as “a dedicated champion for the Parkinson’s community.” Each year, a researcher will be selected who embodies Tom’s ethos - A dedication to groundbreaking research, a commitment to finding a cure and involving people with Parkinson’s in that process.

CPT are delighted that this year’s award was presented to Professor Tom Foltynie. Professor Foltynie is a Consultant Neurologist and Researcher at UCL, London and CPT have been a huge supporter of his work. He plays an active role in recognising the importance of patient involvement in research. Professor Foltynie appeared in CPT’s BBC Lifeline Appeal film earlier this year with Parkinson’s advocates Rachel Gibson and Diane Hastings and with advocate Penny Kustow on Jeremy Vine’s BBC Radio 2 show. We congratulate Professor Foltynie on being the first recipient of this prestigious award.

To read more the *Tom Isaacs Award* go to [www.cureparkinsons.org.uk/ti-award-recipient-2017](http://www.cureparkinsons.org.uk/ti-award-recipient-2017)

We need your help

**Collaboration is key to moving research forward.** Raising issues that are important to the patient community, early in the research cycle, is vital. We want to help make research relevant and feasible, and help deliver the best new treatments for Parkinson’s.

**We need people with Parkinson’s to:**

**Contribute information about symptoms** - We regularly survey PwP’s and this data is vital in shaping our research programme. Keep updated at [www.cureparkinsons.org.uk](http://www.cureparkinsons.org.uk) and twitter @CureParkinsonsT

**Share our research news** - You can help us spread the word to others who might be interested in our work - pass on this newsletter, bring a friend to a research meeting and share our research posts on social media.

**We need you to get involved no matter what level of time and commitment you can give.** If you would like to find out more about how you can get involved, email julia@cureparkinsons.org.uk
The last six months has seen an incredible army of individuals, companies and Trusts support us in a variety of ways. We would like to say a huge thank you to everyone who has supported CPT this year. Our achievements to date have only been possible with your help, and we are so fortunate to have supporters willing to go that extra mile! We have an exciting few months ahead and we would love you to get involved.

We continue to be inspired by supporters taking on personal challenges. This year we have had many fundraisers take part in Tough Mudder events across the UK. Even CPT’s own fundraising team took a break from the cheering squad to take on an extreme 11 mile obstacle course in Henley. The good news is that it hasn’t put them off and ‘Team CPT’ will be back in action at the Ricky Road Run in Hertfordshire on 29th October which they will be running in memory of Tom.

How can you help?

Make a donation
You can use the enclosed envelope, donate online or set up a direct debit to support us with a monthly or annual donation. Every single donation makes a difference to the research we are able to fund.
For further details visit ‘help us’ at www.cureparkinsons.org.uk

Support our events
We run a number of events throughout the year, from our popular Celebrity Comedy Quiz Night (1st November) to golf days and much more.
Please get in touch with anna@cureparkinsons.org.uk for more information about attending an event or maisie@cureparkinsons.org.uk to find out more about sponsoring our events.

Fundraise for us
You can take on a CPT running, cycling or Tough Mudder challenge, or why not create your own event? Our supporters are increasingly organising events such as film nights, quiz nights, “three peaks” challenges and other types of events involving whole communities (such as the residents of Bosham, Sussex, who opened up their beautiful gardens to the public in aid of CPT: thank you, Bosham!).

To get inspired by some of our fundraisers’ stories please visit www.cureparkinsons.org.uk and search ‘Fundraiser News’ or you can email lottie.cureparkinsons.org.uk for more information.

Recommend CPT for support
If you would like to recommend CPT for support from a trust or foundation you know, nominate CPT to become your company’s next Charity of the Year or for matched-funding, please contact maisie@cureparkinsons.org.uk

Leave us a legacy in your will
We want our legacy to be a world without Parkinson’s and a gift in your will could help us achieve this. We have partnered with Farewill, an online will writing service who will provide a free will for our supporters.
You can make your free will today by visiting www.cureparkinsons.org.uk/leave-a-legacy

The Cure Parkinson’s Trust is proud to be a member of the Fundraising Regulator