



Parkinson's
Disease Society

Parkinson's Disease Society

The Research Agenda

Steve Ford

Chief Executive



What are people with Parkinson's looking for?

- High quality services across the country and throughout the whole pathway
- High quality information, advice & support
 - Helpline, website, publications, benefits, CSWs
- **Research improving quality of life for PwP and making progress towards cure**
 - **Active research community**
 - **Balance between short & long term**
- Sense of connection & mutual support for PWP, families & Carers
- To live in a society that knows about and understands Parkinson's
- Needs of PwP integrated into national policy



Stakeholder Groups

Those who have PD now

- Improved treatments
- Disease management
- Enhanced quality of life
- Cure
 - Improvement of symptoms
 - Slowing or halting the rate of disease progression

Those who may develop it in the future

- Prevention
- Cause



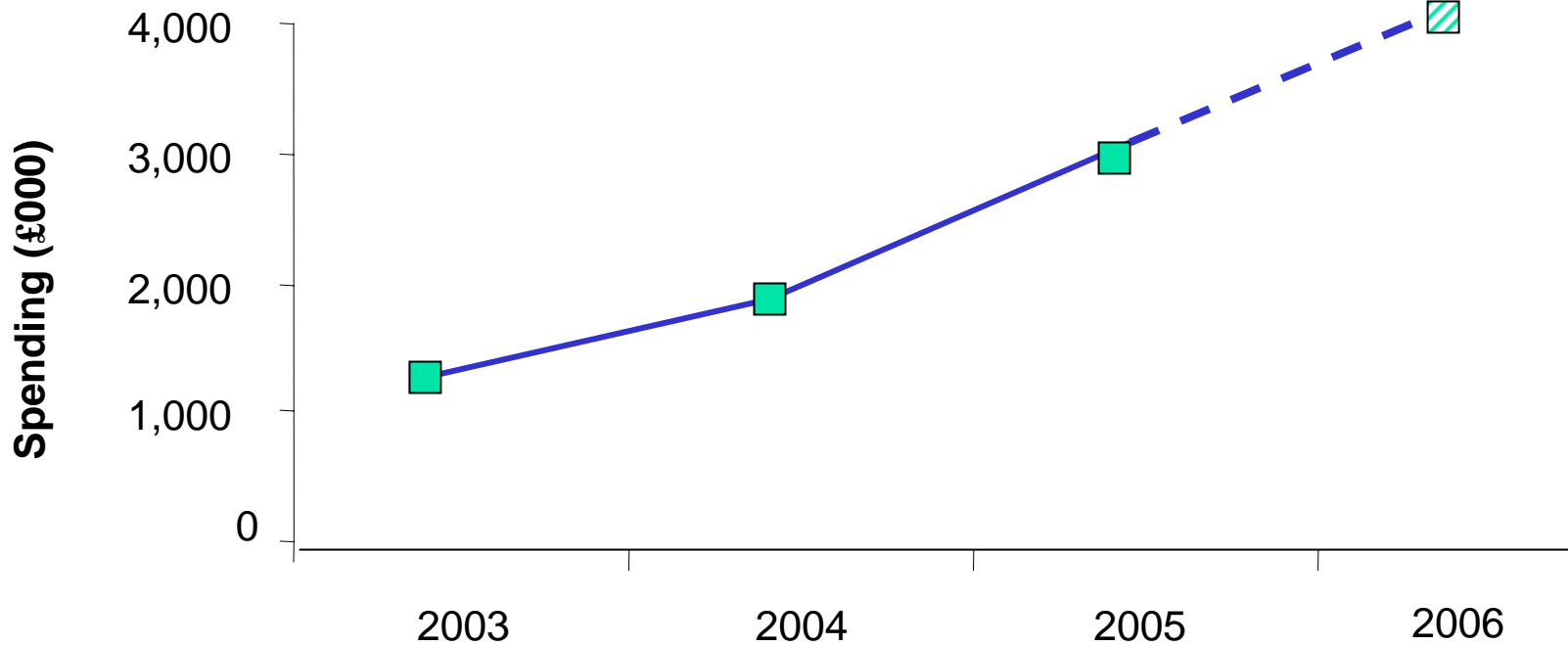


PDS-funded research

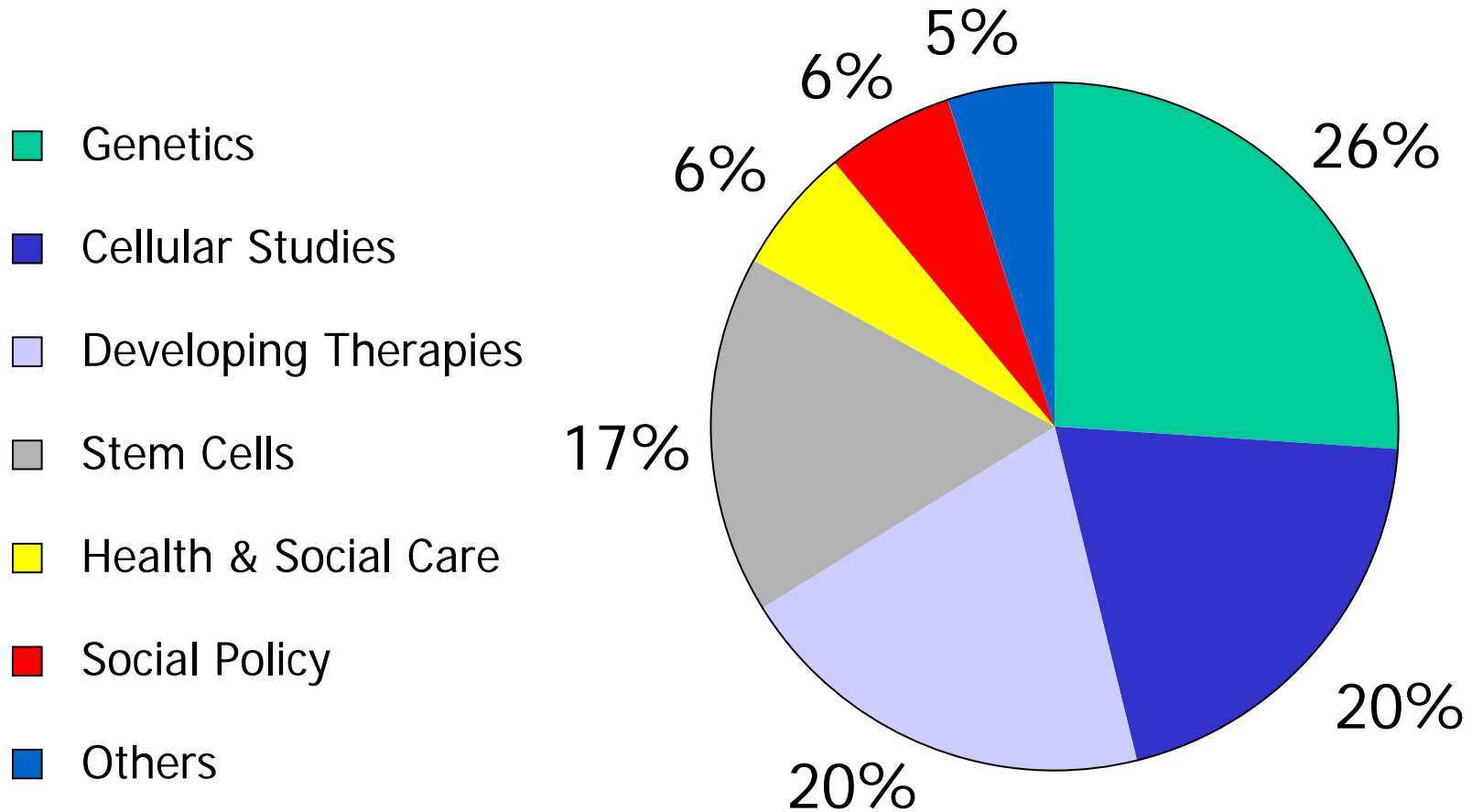
- The leading non-commercial funder of PD specific work in the UK
- Invested over £30m in research since 1969
- Co-funder of projects with other bodies (e.g. MRC, DoH etc.)



Research Funding



Research Support



What is the Research Agenda?

- Forms the basis of the research programme 2005 – 2009
- Generated following input from:
 - Board of Trustees
 - Research Advisory Panel
 - Research Network
 - SPRING
 - Physicians
 - Members of the Society (including one-to-one discussions and ‘round table’ meetings)
 - PDS Staff



Where are we now?

1	<i>Cure</i>	No ongoing treatment (e.g. medicine), no symptoms, no side-effects of the curative treatment
2	<i>Control</i>	Ongoing treatment (e.g. medicine), durable and complete symptom control, few side-effects
3	<i>Partial control</i>	Ongoing treatment (e.g. medicine), control is reasonable but with few side-effects
4	<i>Alleviation</i>	Ongoing treatment (e.g. medicine), control is reasonable but with appreciable side-effects
5	<i>Variable</i>	Treatment requiring frequent adjustment or increase; control is modest, side-effects are present
6	<i>Innovation</i>	Only experimental treatments available; effectiveness unpredictable but possible, side-effects unpredictable
7	<i>No treatment</i>	No available treatments



Realistic ambition within 5 years

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Research Priorities (2005 – 2009)

- Slowing or halting the progression of PD
- Treatment of non-motor symptoms
- The establishment of an evidence-base of ‘best practice’ for the management of PD
- Implementing PD research findings into Practice
- Evaluation of “classical” (e.g. physiotherapy, speech therapy) and complementary therapies
- Role of, and support for, Carers





The way forward

- Involve both the members and the research community to identify key areas of research
- Facilitate new researchers
- Be more proactive
- Be more outcomes orientated
- Improved communication and making better use of the outcomes





Funding streams

- Project/programme grants
 - Up to 3 years
- Career development fellowships
 - Senior research fellowships
 - Clinical fellowships
 - Training fellowships



Funding Streams

- Small project grants
 - Pilot projects
 - Assessment of healthcare delivery to People with Parkinson's
 - Stimulate new researchers (e.g. complementary therapies)
 - International collaborative grants
- Joint projects
 - MRC stem cell fellowships
 - PD-SURG
 - PD MED





Ultimate Aim

To ensure that People with Parkinson's live a life that is free of the symptoms of the condition, however that may be achieved for the individual.





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