

Welcome!

Welcome to the first SENSE-PARK patient-focused newsletter. Whether this is the first time you have read about SENSE-PARK or whether you are already familiar with the project, we hope that you will find the information here of use and interest.

As this is the first edition, it contains a general overview and explanation of what SENSE-PARK is doing as well as who is involved, where SENSE-PARK stands, a diary of events and other news from related projects and organisations. You will also find a topical main article about an important issue for Patients with Parkinson's disease – why measure my Parkinson's?

Any comments or feedback you have about this newsletter would be most appreciated – please let us know what is useful, what is not and what you feel is missing so that we can improve the next edition (probably in around 9 months time).

Thank you for your interest in SENSE-PARK!

What is SENSE-PARK?

SENSE-PARK is a project born out of the urgent need to engage the expertise of everyone involved with Parkinson's to enable the scientific progress that has been made in Parkinson's to be transformed into treatments for today.

SENSE-PARK is a 3 year EU-funded research project focusing on Parkinson's disease.

The project is aiming to develop a device for people with Parkinson's (PwP) that measure their individual disease.

This device will be an unobtrusive and empowering information system for use in the home environment. It will detect and monitor patterns in the condition of people with Parkinson's disease. It will inform the users about motor and non-motor patterns. PwP will measure their condition in daily life activities and while doing leisure activities.

In SENSE-PARK, PwP's are at central positions to ensure the development of a user-friendly and effective system.

Beside providing PwP with more and better information about their disease, there will be other benefits in developing such a device:

- The disease course-associated parameters which are provided to the user can also be provided to the doctor, to enable an intense and transparent at-the-point discussion between two specialists of the disease.
- The system will enable a more continuous, thorough and objective appraisal of changes during disease course with a far wider and more objective perspective, than clinical evaluation can provide.
- If the SENSE-PARK project can find parameters which are associated with the conditions of the PwP's, these parameters can eventually be used throughout clinical trials. Measuring these parameter will then show researchers clearly and accurately whether the treatment being tested has had an effect or not.

Who is involved?

For projects like this to be successful, the collaboration of many professionals with different skills is required. There are 7 European partners involved in the SENSE-PARK project coordinated by Dr Holm Graessner at the University of Tuebingen, Germany. For example, some are well placed to determine the needs and requirements of people with Parkinson's when measuring their disease and others are experts in sensor development, data analysis, interface adaptation or project management. A very crucial partner is also the Cure Parkinson's Trust whose job it is to make sure patients are equally involved throughout the project and that they are kept informed about SENSE-PARK progress. The project's

website has details about the 7 partners at www.sense-park.eu

Why measure my Parkinson's?

A personal account from Tom Isaacs, President and Co-Founder of The Cure Parkinson's Trust



When you are diagnosed with Parkinson's it really does feel like everything has gone horribly wrong. The shock of being told you are living with an incurable, degenerative neurological illness provokes first shock, then anger and this is quite often followed by a period of denial.

But Parkinson's is not a death sentence, it is a life sentence. It is something that everyone who has it has to learn to live with. Despite this, many people do not actually proceed beyond the denial stage choosing instead to ignore it. Those that do ignore it tend to dwell on the things they can no longer do as well as they used to. They become very isolated, selfish and inward looking; this is not a healthy place to be.

Those people with Parkinson's who do get beyond the shock, anger and denial stage are better equipped to cope with Parkinson's and they can begin on a much more positive journey.

So what has SENSE-PARK got to do with this?

For me SENSE-PARK is one of the exciting initiatives that The Cure Parkinson's Trust has allowed me to become involved with that is helping to provide the tools to progress on that journey and to make a difference to the speed by which we all may travel.

What I think we are after with this project is a product which allows us PwP's to better communicate our Parkinson's, to engage with it and to become more

knowledgeable about its particular effect on us as individuals. In order to regain some of the control we have lost through having Parkinson's, we need personalised, objective, patient-centred continuous measures for Parkinson's.

I'll take those points individually.

Personalised because no two people with Parkinson's have the same symptoms and it is crucial that only the symptoms that are relevant to an individual are taken into consideration.

Objective because to have any credibility or resonance with the scientific community, analysis of Parkinson's must not be opinion based. So, what is needed is something tangible which can be measured without being in any way subjective or opinion based.

Patient-centred because we are all individuals and what may be important for one person with Parkinson's may not be important for another. Also, it is crucial to have a personal perspective of the condition. I know from my own experience that on the day I visit my clinician I will look as though I barely have Parkinson's. You can rest assured that the day before and the day after I will be – to use Elvis' words, "Shakin like a leaf on a fuzzy tree..." It is certainly not unusual to present atypical symptoms to your clinician which gives a false impression.

Continuous because currently the average consultation time in Europe for people with Parkinson's is 12 minutes ; it must be obvious that in these 12 minutes you are only getting a snap-shot of the full range of symptoms one can experience.

In fact, using one word, "*Parkinson's*", to describe everything and everyone that falls within the parameters of this condition simply does not do justice to the scope of the problem. Too often

Participants:

Eberhard-Karls-Universitaet Tuebingen, Instituto de Medicina Molecular, Universitetssykehuset Nord-Norge HF, The Cure Parkinson's Trust, Hahn-Schickard-Gesellschaft fuer angewandte Forschung e.V, .Abilitynet, Hasomed Hard- und Software fuer Medizin Gesellschaft mbH

Parkinson's is thought of and treated in terms of its stereotype. So many people, including some neurologists (!) think of Parkinson's only in terms of slowness of movement and shaking. This is only the tip of the iceberg.

Parkinson's affects young and old, rich and poor, every creed, colour and religion. It affects you physically and emotionally and it compromises everything that you once took for granted – movement, communication, cognition and mood.

It does all these things and yet, I repeat, every person's symptoms are different and the symptoms experienced by the individual can vary massively from day to day, hour to hour even minute to minute.

Take all the above into account and you realise how difficult Parkinson's is to live with and also how impossible it is to work with your healthcare advisors to establish the optimum treatment plan throughout your Parkinson's journey.

With such a complex illness, the engagement of the people living with the condition is crucial to ensure their quality of life is as good as possible and we need the means of recording and conveying the personal condition to those that can help to make a difference to the this quality of life.

So SENSE-PARK is for me, and for everyone with Parkinson's, a hugely important project which goes beyond simply providing a tool or tools for people with Parkinson's to better manage their condition. I think this project has far greater implications than this and if we get it right, could change Parkinson's culture making it more relevant, more focussed and in the long run, will contribute to the marriage of patient needs with scientific knowledge which is something which is so lacking in Parkinson's at the moment.

SENSE-PARK - your Parkinson's, why measure or record?

An 'outsiders' view from Joy Duffen of The Cure Parkinson's Trust



There was a time when nothing much seemed to be happening in improving the lot of those with Parkinson's. L-Dopa was the wonder drug of its time and there was little competition. Were there enlightened

neurologists in the early days who, nevertheless saw that Parkinson's was a complex whole person phenomenon and not just a movement disorder presented as tremor of the elderly? Perhaps there were and perhaps the need for better observation was apparent even fifty years ago when L-Dopa treatment became the immediate port of call for "curing" the problem.

I have been interested in Parkinson's for many years back to my first introduction to medical matters, from my early years studying veterinary medicine and because of the peculiarities of my course and the fact that we had outstanding tutors instructing largely on human neurological functions and anatomy. It still remains a bit of a mystery as to why we do not see a Parkinson's equivalent in any animal species although the symptoms can be induced by various means, one observation of the injudicious use of some recreation drugs in man leading to some early understanding of certain causes and effects and the creation of an animal model.

But why now more than ever do we need to concentrate on better ways of assessing the whole complex, personal phenomenon that is Parkinson's?

"The Cure Parkinson's Trust's role is to ensure that people living with Parkinson's inform this project every step of the way."

Helen Matthews - The Cure Parkinson's Trust

Why measure it if you cannot do anything about it?

In the course of my more recent years in which I have been involved in the field I have been amazed to learn of the range and variability of the symptoms that characterise this condition. I had thought that I knew quite a lot about Parkinson's and I am certain that as a lay person I do know more than most but what a revelation my involvement with The Cure Parkinson's Trust and the SENSE-PARK project has brought. Why did I not realise that pain, sleep disturbances, issues with speech, never mind freezing and problems with balance were just a few of the symptoms that can cause most distress to so many with Parkinson's? Perhaps because I had never before been exposed to or listened enough to those who have the condition!

It is time to listen to those that know best and try to meld that invaluable experience with the specialist knowledge brought by the most enlightened and able individuals who are the health professionals who can direct the route of treatments to optimum benefit.

Two compelling reasons to be measuring as much as we can as well as we can right now:

1/ Those neurologists on whom those with Parkinson's most depend to guide them in achieving the best quality of life already have an armory of drugs and interventions that can really make a difference if they can but properly measure and monitor what is going on.

2/ We are on the cusp of the most exciting time for the treatment of Parkinson's, the amazing expansion of understanding of the mechanisms, biochemistry, neurological function, target interventions and genetics is about to unleash a whole new war chest of drugs and interventions that could make a difference like never before. However we must be able to assess

their effects properly to pick up the subtle changes these treatments may induce. As this way we can prove the effectiveness of new treatments that move us closer to a cure.

Where does SENSE-PARK stand?

SENSE-PARK has started in October 2011 and has already achieved the following things:

For the device:

- SENSE-PARK first tried to define the needs and requirements of PwP through a survey that was sent to PwP by Cure Parkinson's Trust in autumn 2011. 198 respondents who answered the survey provided among other things information on the most important symptoms and predictors for PwP.
- Clinicians involved in SENSE-PARK provided a narrative review about useful parameters to be detected by the SENSE-PARK system
- The SENSE-PARK consortium reached an agreement on what symptoms to follow in the SENSE-PARK device and on what symptoms to include into the first pilot system
- The first pilot system has been consented and is currently being built and tested.

For the interface:

- SENSE-PARK sent another survey to the respondents of the first survey and gathered information on IT usage of these PwP.
- The project is now moving into the requirement phase where the needs of the individual will be addressed.