



ParkinsonNet, a warm bath for people with Parkinson's, a Blueprint for other healthcare disciplines

Dear reader.

In response to your interest in introducing ParkinsonNet in your country, we, the Parkinson community in the Netherlands, would like to share our vision about ParkinsonNet.

On Saturday, April 13, 2024 ParkinsonNet founders Marten Munneke and Bas Bloem received a royal award from Minister of Medical Care Pia Dijkstra. The ceremony took place during the annual World Parkinson's Day 2024 Symposium, organized by the Parkinson's Association in Nieuwegein. Marten Munneke was appointed Officer in the Order of Oranje-Nassau and Bas Bloem was appointed Knight in the Order of the Dutch Lion.

The reason for this was that we people with Parkinson's disease in the Netherlands it is a special achievement to make ParkinsonNet so easily accessible for us. A platform for us Parkinsonians, where we can approach care offered by passionate care specialists. It is a blueprint for other healthcare disciplines in other healthcare fields.

Below are several anecdotes from the testimonia, written by some of us,

Subject: nomination of the award of the King of the Netherlands

Moving from idea to ambition and finally realising an indispensable concept: ParkinsonNet. We as "people with Parkinson's" can be very happy with so much expertise in the field of Parkinson's, which means that we can see many specialized healthcare professionals among our practitioners today. It is an example for other domains.

(Marjan Overdiep, Parkinson's Working Group and Work Parkinson Association, MarYoga Foundation | Yoga4Parkinson)





I wholeheartedly endorse the request to award Marten Munneke and Bas Bloem for their commitment to Parkinson's Patients and their loved ones during almost their entire careers. Marten and Bas founded and designed ParkinsonNet. Doctors and paramedics are given extra training to be able to provide specialist care to people with Parkinson's and Parkinsonisms. The national network that has been created as a result is invaluable for this.

(Monique Bosman, Chairman PK-PAR Parkinson Association, Member WAR ParkinsonNL)

Bas and Marten, together you have created a wonderful multidisciplinary care network as the founders of Parkinsonnet. This makes it super easy for us as a patient to find all the necessary, and more importantly, specialized, care providers in the area. This has resulted in a huge positive improvement in terms of the quality of care and ultimately the quality of life for us as patients. And how proud can you be of the fact that your beautiful concept is currently being adopted in several other countries?

(Annelien Oosterbaan, colleague and experience expert)

Prof. Dr. Bastiaan R. Bloem (Bas): you are internationally recognized for your work in the field of Parkinson's and the many structured and coherent research done on the treatment and care of people with this condition. Bas, you are co-founder of ParkinsonNet and have contributed to the development of this network to improve the care for Parkinson's patients. Applied science, in addition to the many fundamental research carried out by you and your team.

Dr. Marten Munneke also co-founder of ParkinsonNet, you have been committed to connecting healthcare providers and optimizing care for people with Parkinson's. Together a golden team.

(Ruud Overes, On behalf of the Parkinson2beat team)

ParkinsonNet started 24 years ago as a collaboration of a few enthusiastic young neurologists (Marten Munneke and Bas Bloem) with some physiotherapists from Nijmegen, but has since grown into a national network of healthcare professionals in the field of Parkinson's (think of neurologists, Parkinson's nurses, physiotherapists, speech therapists, dieticians, etc.), so that as a person with





Parkinson's you not only know where to go with your questions and challenges, But also be sure that you will find healthcare providers who have the most up-to-date knowledge in the field of this condition. I think there are few other conditions for which care is as well organized as for Parkinson's. A real blessing in disguise when you hear the diagnosis.

(Dominique Prins-König)

ParkinsonNet is a national network with more than 4,000 healthcare providers specialized in Parkinson's. A formula for success, because this network is now also being rolled out in other countries, following the example of the Netherlands. What drives ParkinsonNet: the best possible care and quality of life for everyone with Parkinson's disease or atypical parkinsonism. By putting people first, improving collaboration between different healthcare disciplines and increasing the expertise of paramedics, ParkinsonNet facilitates an optimal network of Parkinson's specialists. Joining forces. In this way, ParkinsonNet contributes to a high quality of care. Through Parkinson Care Finder, anyone can find a specialized care provider in their area. Research has also shown that the costs for people with Parkinson's in regions with a care network are lower because complications are prevented, and care is improved. In the current time when healthcare costs continue to rise, this is a not insignificant aspect.

(Gijs de Vries (1959), Parkinson's patient (diagnosed at the age of 50))

Bas Bloem works hard together with Marten Munneke to make the lives of people with Parkinson's as good as possible, thanks to the organization ParkinsonNet. This organization trains care providers to specialize in Parkinson's and to propagate and support this worldwide. So that every person with Parkinson's has a medical support team behind them! Whatever bread is needed! (Sabine Woertman-Bode, I live and dance with Parkinson, Remedial Therapist

(Sabine Woertman-Bode, I live and dance with Parkinson, Remedial Therapist Dance teacher - inclusive dance)

As a young person with Parkinson's disease, I benefit greatly from broad-based and coordinated integrated care. In other countries, but also in the Netherlands, this is not as organized for many diseases as it is for Parkinson's disease. This is partly due to the tireless efforts of men such as Marten Munneke and Professor Bas Bloem. In





fact, the quality and coordination are such that, and I have seen it several times when I was at Radboudumc for scientific research, delegations from other hospitals or from other countries were updated and shown around.

(Peter van den Berg, Young and Parkinson)

After my Parkinson's diagnosis in May 2019, I didn't know what to expect. My neurologist also linked me to my Parkinson's nurse, and she pointed me to the ParkinsonNet platform, where I could choose my own healthcare professionals, such as physiotherapist, occupational therapist and others I thought needed them. First a physiotherapist was selected, then an occupational therapist and speech therapist. All very nice people say 'Whoppers' with a lot of knowledge. To this day I am in contact with my physiotherapist and recently also with my occupational therapist. I am very grateful that we, people with Parkinson's, can have such a well-disciplined team.

A blueprint for other healthcare disciplines! (Hans van Geluk, Parkinson and Traffic Participant)

Perhaps most important is their tireless commitment to making ParkinsonNet a success. The fact that almost 20 years ago they were the founders of this network in which caregivers, doctors, patients and their loved ones are brought together to give extra attention to everyone with Parkinson's.

Without Bas Bloem and Marten Munneke, ParkinsonNet would not have existed, and I am sure that the world of many patients would have looked different. Finally, I would like to mention the set-up of Parkinson TV. The many recordings that have been made for this show how complex this disease is and because of all the recordings a true encyclopedia in the field of Parkinson's has now been created. (Jan van Hasselt)

Note: all added anecdotes from fellow Parkinsonians are posted with permission.

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