

Royal Honour for Johan Godfriedt Beun
't Harde, September 7, 2019

Ladies and gentlemen,

It is an honour and an exceptional pleasure for me to be able to address you on this occasion.

Special meeting

Today, as Mayor of Elburg, I have the honour to be present at a special meeting: a special extraordinary meeting of the steering committee of the Dutch Adrenal Patient Society NVACP and the AdrenalNET.

Both boards have chosen to hold this meeting here in 't Harde, and that's not without reason. Because 't Harde is the residence of a prominent person who is involved in both the association and the foundation. And you've guessed it: that is Mr. Johan Beun. And it is to you, Mr. Beun, that I'm going to address myself especially.

Family and acquaintances

It is very nice to see that not only so many acquaintances from your network, but also your wife Marjo, your two daughters Kirsten and Eva, your son-in-law Jordi, your brother and sister-in-law, not to mention your grandchildren Sarai and Oscar, are also present here. And as I understand it, we even have a childhood friend from India in our midst. That makes this meeting all the more special.

Special merits

Dear Mr. Beun, dear Johan,

Without any hesitation I can say: you are a man of special and extraordinary merit. You regularly refer to yourself as being "in charge of empty boxes" or "chief empty boxes". Modesty adorns mankind, but with this qualification you are not doing justice to reality!

For more than three decades, you have worked very intensively, on numerous fronts, both at home and abroad, with great dedication and an extraordinary enthusiasm for the quality of life of patients with a rare adrenal disorder. These patients are confronted with the consequences of their disease for life. You - yourself an "expert by experience" - have taken the fate of these patients to be heart and consider the improvement of their situation and position to be your personal mission and life's task. As I understand it, you were inspired and urged to do so at the time by the then Minister for Health, the late Mrs Els Borst.

In 1988, you were one of the founders of the Dutch Adrenal Patient Society NVACP. From its founding to the present day, you have worked as a volunteer for this association, free of charge. From 1988 to 1997 you were chairman of the association and since then you have been an advisor. And you are still a driving force behind the association, now with the status of an honorary member!

You were one of the initiators of the establishment of the highly innovative national multidisciplinary platform BijnierNET known abroad as ADRENALNET. You have made an essential and indispensable contribution to the success of AdrenalNET and, as coordinator/director, you are the major driving force behind the work of AdrenalNET. You have done a great deal of work in setting up the BijnierNET website and in creating and implementing the quality standard for Adrenal Diseases. In addition, you have organised a large number of information meetings for patients and caregivers, and you devote a great deal of time to answering the numerous questions from patients. Thanks to your efforts, a large number of innovative products have become available to patients, such as emergency cards, the adrenal app, but also something as basic and effective as a pacifier that helps

young children to take medicines. In addition, as a representative of AdrenalNET, you are involved in a large number of committees and maintain numerous external contacts, for example with the organisations for general practitioners, specialists and nurses. In recent years, you have been very efficient in disseminating the Adrenal philosophy throughout Europe and, within the European Reference Network for Endocrine Diseases, you have become the most important stakeholder in Europe for the patient with a hormonal disorder.

In 2001, you were one of the founders of Nictiz, the e-health expertise centre/NGO in the Netherlands and from the very beginning you were a board member on behalf of the Dutch Patients and Consumers Federation NPCF. Until 2009, you were an ambassador for Nictiz and an international advisor to various countries, ministries and organisations in support of the development and implementation of electronic patient records.

You have been, and still are, an advocate of the patient perspective in the informatization process in the healthcare sector. You have done pioneering work in the field of e-health. You have done a lot of advisory work for ZonMw, the Dutch NGO organisation for the promotion of health research and the implementation of newly developed knowledge in the field of healthcare. At ZonMw, you made a major contribution to the field of new technologies in healthcare. For example, you were involved in the creation of new programmes, you were a member of programme committees and you assessed many research projects.

Internationally, you are strongly involved in the European Reference Network for Rare Endocrine Disorders, Endo-ERN.

In 2000, you were the founder and for 17 years afterwards chairman of the ADRENAL-fund, a foundation whose purpose was to initiate and support research on behalf of the members of the Dutch Adrenal Patient Society NVACP.

In addition to the activities mentioned above, you have worked in many other fields and in many other ways, both nationally and internationally, and you have made many many worthwhile contributions in the field of adrenal patient care, especially adrenal patients. In this context, we can only mention, among other things:

- Member of the board of MPZ (Millennium Platform for Care);
- Vice-chairman of the NPCF (Dutch Patients and Consumers Federation);
- Advisor to IGBZ (Healthcare Information Security Foundation);
- Chairman of a large number of national and international committees, organisations and conferences in the field of electronic patient records, standardisation and patient interests.

The number of hours you have invested and are still investing in all these activities far exceeds a regular working week. To make this possible, you finished your work as an entrepreneur a few years ago.

Thanks to all this hard work, you are particularly appreciated by both care providers and patients. Both nationally and internationally, you are seen and recognized as the representative of the voice of the patient with a rare hormonal disorder. When we take into consideration that you yourself are an experienced health consumer and everything that comes with being a patient, it makes your performance even more impressive.

Mr. Beun as a 'human being'

I have already said a great deal about your performance and merits, and there is much more to be said about that. But who is Mr. Johan Beun as a human being? In order to get an idea of this, I consulted a number of people who know you well. It will not surprise you that Marjo is one of them.

The lines are short, aren't they? (*Marjo is an employee of the municipality of Elburg and in that sense a colleague of the Mayor Jan Nathan Rozendaal*).

What a person does, how and for what a person commits himself and what a person professes to do, says a lot about who he is. But of course a person is more than what he does and performs. When I look at everything you have done and try to let all your achievements have an effect on me, my conclusion is: there must be a certain personality type to match. Someone who succeeds in doing all this must have an enormous drive, a great level of perseverance and an unbridled appetite for work. And that is indeed the case. You are described as a first-class go-getter, a super optimist, and as someone with extraordinary willpower and decisiveness. Once you've thought of and figured out something, you won't rest until it's actually realized. And then it will also BE realized, if possible yesterday already. When it comes to you, the words 'terrier' and 'bulldozer' are also used. What this means is that if you get stuck into something, you won't let go and nothing will stop you from reaching your goal. That goal is not your own interest, but always the higher interest of improving care for adrenal patients. And yes, you are a bit demanding. It can happen that you send an e-mail to someone at 23.45 hrs. and send the addressee an e-mail again the next morning at 7.00 hrs. with the question: have you read my e-mail yet? At meetings you are always emphatically present and in discussions you are always right. Because if you're not sure, you won't even start the discussion. And with all that, according to the insiders, you're just a sweet man (I can't divulge from whom that qualification comes). You are friendly and caring and would certainly go through fire for your children and grandchildren.

I could say a lot more about you, but I want to stop there, because I don't want to put your modesty to the test too much.

Thanks, recognition and appreciation

Your dedication, unbridled and disinterested efforts and the great significance of your activities in the interests of patients in general and of adrenal patients in particular, and thus for health care in the broadest sense of the word, deserve thanks and appreciation.

But how can this gratitude and appreciation best be expressed? There are many people who have looked into this. And all those people and institutions, including ultimately His Majesty the King, have judged that a royal decoration is an appropriate token of recognition and appreciation for everything with which you have done, and are still doing, to your credit.

Johan Godfriedt Beun, because of your efforts and achievements and considering the duration, diversity, scope and the national and even international character and significance of your activities, as I have just summed them up briefly, His Majesty the King has been pleased to name you Officer in the Order of Orange-Nassau.

Congratulations

Congratulations on this well-deserved Royal Honour!

I also like to congratulate your wife, your children, your grandchildren and other family members.



Jan Nathan Rozendaal

Mayor of the city of Elburg