



## Remembering GertJan van Ommen

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**One could say that GertJan was a man of contradictions. He started his journalistic career as a rock music critic and finished it as the distinguished editor-in-chief of the EJHG. He was fiercely competitive, yet overwhelmingly supportive of others in the field. He was an intensely serious scientist with a great sense of humour who loved to dance. He liked to argue, but at the same time bring people together. He talked with the same enthusiasm about his work and his family (including the dogs).**

**GertJan (or GJ, as he more often called himself) was the sum of all these parts, and more. Some of his friends and colleagues have provided their memories of an exceptional human being.**

“I’ve known three different GertJans. The first was the young scientist who brought a molecular approach to Leiden, and who was so clever at devising little tricks and taking original approaches. He would adapt novel technologies and apply them - mainly to Duchenne but also to many other genetic questions and problems. He was very innovative – he didn’t invent assays but he could see the assay’s broad vision so he could apply it in a really meaningful way. He was very smart, and very competitive, and he was also very communicative, so he was always very visible in meetings and conferences. His aim at that time was directed to the problem of Duchenne dystrophy to which he contributed so much – first in trying to find the gene for it and then in devising proper assays to test for the gene because the gene is so big that no lab in those days could test it completely.

And then at some point, I think before he retired, he developed this other person where he would bring people together and find a common goal and a common purpose; he would get people working together to get something done. He was brilliant at that, and perhaps that was connected to his way with words, his approach, and his sense of humour. He could sit through a very long meeting and stay focussed. If you can do that, you often end up in politics, but he didn’t – he stayed in science. But in some way, he was in politics because he would take on a task and get people organised in a way that would lead to success, and that would be of great benefit to everyone. He’d get everyone involved, and whatever the question, you knew the process would be fair. It might be long and laborious, but because of his staying power he could do that. He did it for the Human Genome Organisation – that was his first - and then for many other people, for ESHG, for a number of research organisations, for BBMRI-ERIC, the European BioBanking infrastructure, and so forth. We had always respected him, but that’s where we all came to love him. He was such a communicator and so good at bringing people together.

The third GertJan was the personal one. He was funny, he was interested in everything – not just genetics – and also you could talk to him about anything. He was very open. When he became ill you could talk about that. You could sit down with him and have a real heart to heart; he had a fantastic ability to connect and establish a personal relationship with a large number of people. And all of it was real; nothing was invented. He was not a politician in that sense. He didn’t hide anything and would talk quite openly about difficult things. He always made you feel acknowledged and listened to, and he had a huge ability to give affection and understanding and to

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make people feel valued. It is this third GertJan that I will miss the most.”

**Han Brunner**

“I knew GertJan since the early 1980’s, both through his work on developing RFLPs for the mapping and diagnosis of X-linked diseases. He was a major contributor to X chromosome mapping meetings, as well to all workshops on mapping and cloning of the gene responsible. GertJan was not only a very bright scientist in the field, but he was a very generous collaborator. Whilst working in Peter Pearson’s department in Leiden, his group developed some of the first probes which were subsequently used for the first prenatal of Duchenne muscular dystrophy (DMD). I was working in Bob Williamson’s laboratory at the time and GertJan visited us with Peter Pearson. It was clear that the markers GertJan’s group had developed together with our own could potentially allow the first prenatal diagnosis of DMD using flanking markers. One of these probes (then called 754) was used to confirm that the patient BB, used by Kunkel’s group to identify the gene, had a deletion in Xp21.

GertJan was one of the major organisers of the early workshops on identifying the DMD gene, often held in Holland or the UK. His generous spirit and promotion of the sharing of data facilitated the hard work that was needed to clone the gene. I particularly remember the collaborative spirit of the workshop held in Holland in 1984 when most of the major players attended. The race for the gene was highly competitive, but GertJan was one of the scientists who ensured a healthy debate, which advanced the field.

Over the years, we met regularly at genetics meetings both in Europe and the USA. We had many discussions over beers in the bar with the late David Cox who had a common interest in Huntington disease and chromosome 4. GertJan went on to develop oligonucleotides for exon skipping as a therapy for DMD. He chaired the scientific advisory board of Prosensa, which was set up to take this approach to the clinic. He was one of the pioneers in this field and challenged us all in making the right decisions to design the best oligonucleotide sequence to skip exon 51. He was a great team player, supporting his team led by Judith van Deutekom.

It was always a pleasure to collaborate and discuss human genetics research and even editing journals with GertJan. I shall miss him.”

**Kay Davies**

“It was with great sadness that I learned of the untimely death of GertJan van Ommen. I admired him as a scientist and leader of a great research institute in human genetics, together with his beautiful work on Duchenne and his commitment to translational research, and his more than 20 year-long efficient dedication to the European Journal of Human Genetics, which afforded me the pleasurable opportunity to meet him once a year at the Editorial Board meeting at the ESHG conference.

GertJan was also a long-standing friend, even though our meetings outside of what was strictly business were not so frequent. Starting in the late 80s, I always enjoyed these occasions, where I could appreciate his humour and conversation together with our shared enthusiasm for human genetics. I particularly remember some Human Gene Mapping meetings (notably an X chromosome one in beautiful Amalfi), and the Human Genetics courses in Sestri Levante, with their very friendly atmosphere. I especially remember, at one of these courses, the hilly walk at the Cinque Terre with students and faculty, where GertJan helped me carry the heavy bag that I had taken thinking I would work rather than follow the walk. GertJan wrote later that it was during the dinner that followed in a favourite small fish restaurant, where we were joined by Marcus Pembrey, that he decided to be a candidate for Chief Editor of EJHG.

We also had some more recent family encounters, with Ria and my wife, at the Petite France in Strasbourg and a leisurely walking tour together in Berlin. I will miss GertJan greatly.”

**Jean-Louis Mandel**

“I first met GertJan when I was a PhD student in 1989 and he was my supervisor. My thesis was on facioscapulohumeral muscular dystrophy, a subject close to GertJan’s heart. We had contacts now and then because we went to the same meetings. He didn’t have too much to do with the day-to-day work on my thesis, but he had to officially say that everything was OK. I remember that one evening he asked me to

come by to discuss it. In the Dutch system you have propositions in your thesis – statements about various issues. GertJan said it was very well written, but he wanted to discuss my final proposition, which was not directly related to the content of my thesis but related more to the PHD student system generally. We didn't agree on it and argued all evening. In the end I had to take it out – he was the boss!

I went to the US as a post doc, and then I was offered a position in Utrecht a couple of years later. GertJan was not amused because he wanted me to come back to Leiden. So, he bought me a business class ticket and arranged a dinner in a Michelin-starred restaurant to try to convince me. But I decided against it. That was the only moment when we didn't get along too well. But it didn't last long and later on we worked very closely together in the arena of the biobank.

I appreciated the fact that he always had a thousand ideas and the ability to really connect things that looked completely independent of each other. He was a real visionary; we went down the biobanking road quite early on, writing our first grant application in the field in 2005, long before people thought biobanking was really important or necessary. He also really cared about people and had very broad interests. That's clear from his career, as is the fact that he wanted to make the world a bit better – that was one of his driving forces.”

**Cisca Wijmenga**

“My professional life ran parallel to that of GertJan for more four decades and we became good friends. In the 1980's, as we were establishing our molecular diagnostic laboratory in Newcastle, GertJan's work alongside Johan den Dunnen and others, was an exemplar of international collaboration that set the bar for the years to follow. GertJan insisted on making the linked probes freely available, thereby ensuring the research reached clinical utility in the shortest time. We met regularly at conferences and in particular at the European course in Sestri Levante in the 90's before Giovanni Romeo moved to Bologna and the course was re-established in Bertinoro.

GertJan was a unique and inspiring teacher. He never cut corners and was intensely focused on maintaining academic rigour with his sharp style of questioning,

but he also had an eye for theatre. The outstanding moment at the Sestri course was the way he presented the work from Leiden on multicolour Fluorescent In Situ Hybridisation; he steadily built to the final slide displaying the rainbow karyotype, eliciting an outburst of spontaneous applause. He was always careful to acknowledge those responsible for such advances but also clear sighted on making real progress and ensuring effective translation into patient care. Others are better placed to recount his many other academic achievements, but I would also like to add my admiration for the diligence and commitment he showed in building the European Journal of Human Genetics into such a valuable resource, providing an excellent outlet for our field and ensuring that the European Society prospered. I have been honoured to be part of the editorial committee.

It was at an ESHG meeting that Gert Jan came up to tell me that after listening to one of my talks he had had an endoscopy and been shown to have an operable colorectal cancer. His gratitude was genuine, as was mine that he should want to credit me with having helped. In recent years we shared personal experiences of prostate cancer. Mine was caught early and amenable to surgery but his was not. He approached his time as a patient on a series of interventions with the same clear analytic approach that he brought to his work and he negotiated his subsequent treatments as a full member of the team.

I was deeply saddened to learn that he had died. I hope his great contribution is remembered for many years into the future.”

**John Burn**

“We have lost an exceptional colleague. GertJan was the best friend of my professional life in genetics. I admired and enjoyed his cleverness, his culture, his creativity, and his open-mindedness. Rather than fighting for leadership in his own field, he opened many doors to many people in many areas. He was a paradigm - a world-class scientist, with insatiable curiosity and enthusiasm regardless of potential personal rewards. The world would be a better place if populated in his image.

I really discovered his humanity at the European School of Human Genetics in Sestri Levante, in 1992.

He was always surrounded by myriads of students, loving his conversation and his joy of life. After having given a beautiful scientific talk, he was one of the first to dance at night, and among the last to go to bed.

Since then, I watched his personal professional development and learned a lot about how to develop a field and build collaborations with scientists from other fields, and how to enlarge the vision and pave the way for useful innovations. The two of us were convinced of the importance of building up the ESHG. We often exchanged views about it, GertJan as editor-in-chief of the EJHG and me as chair of the PPPC. Once again, I was amazed by his capacity to be both visionary and caring about people. This combination is precious in the development of innovative approaches to serve real, necessary goals. Very often, when someone is able to give so much, it is because this person is not alone in life, but skilfully supported by a companion. Behind Gert-Jan, there was Ria. Thank you, Ria.

As a friend, he was just delicious, entertaining, simple, and direct. I will miss him a lot.”

**Ségolène Aymé**

“We geneticists understand that there is extensive genomic variation, and therefore each genome is different from all the other ones on earth. This makes each one of us a unique personality... This is particularly true for Professor van Ommen, the dear friend and colleague GertJan! Reflecting on his important presence in the scientific world, I cannot find a similar personality; he is therefore irreplaceable! I wished I could have had a peek into his unique genome to find out the variants that have made him what he was. An outstanding human geneticist, a sophisticated thinker, an eloquent speaker, a politically complicated personality, an elegant fighter, an amusingly opinionated scientist, a humbly proud individual, a constructive behind-the-scenes manager, and a truly amusing personality for a discussion over an after-dinner cognac!

His contribution to the search for the causes and therapy of Mendelian genetic disorders was truly outstanding, and for that I applaud and celebrate his life. His contributions to the Human Genome

Organisation (HUGO) among other professional societies of scholars were also exceptional and remarkable. His dedication to the European Journal of Human Genetics was exemplary in scientific publishing. His presence in shaping up genetic medicine in The Netherlands and Europe was towering.

I will keep his memory in a very special place in my mind. Thank you, GertJan, for your science and style!”

**Stylianos Antonarakis**

“I regret, like everybody else in the ESHG, the sudden disappearance of GertJan with whom I shared a lot of memories about the first steps of our Journal, founded when I was the first democratically elected President of ESHG and became the first EJHG Editor in Chief.

Today the challenge of our Society will be to find the best possible successor for GertJan. We are experiencing the most important transition ever from human genetics into genomics, and since the EU-supported “One Million Genomes” project is not dependent on technology only, we need to create the cultural background in which our journal can play the leading role in Europe. Choosing the best successor for GertJan will be a way of honouring his memory.”

**Giovanni Romeo**

“The care, time and attention that GertJan spent on the journal and his willingness to try new things - like a social media strategy - to develop the journal and communicate the important science it reported are the things about him that will stay longest in my memory. He was exceptionally skilled at turning cumbersome, complicated scientific concepts into digestible, understandable paragraphs in lay terms that people would read on social media. He had a deep understanding of the science and also knew how to communicate it to lay audiences in an engaging manner.

I first started working with GertJan around September 2018, so I only knew him for a couple of years. But during that time, we spoke once or twice a week about the journal or social media things, and so we had a lot of contact. I was very grateful to him for the amount of time he spent and his patience in helping

me as an editor to understand how to select the best papers for a journal, what the most important science was, and what would be the most attractive to readers.

I'll miss very much his experience and constant advice about how to communicate science and how to run a journal."

**Alisdair McNeill**

"When I think of Gert-Jan I mostly remember his ESHG presence, with his characteristic opening of each question posed to a speaker with 'Van Ommen, Leiden'. It must be an exaggeration, but in my memory Gert-Jan asked questions in every session that I attended in my first ESHG years. Later as an ESHG Scientific Programme Committee member, I learned to appreciate his active participation and broad interest even more, there is nothing worse than silence after a presentation. Of course, Gert-Jan also fanatically and without inhibition promoted the EJHG at our conference, I am sure he raised the impact factor of the Journal by a few points himself.

Above all, he was such a friendly person, genuinely interested in people and great to spend time with. Fun was when he once joined me and my wife in a taxi after the ESHG party, we both remember him as a person with a young spirit. There are very few people as dedicated to human genetics in Europe as Gert-Jan, the ESHG will not be the same without him!"

**Joris Veltman**

Some emails from GJ to **Stanislas Lyonnet** illustrate different aspects of his character:

**Laconic GJ** June 2008

Seems he likes ANY suggestion. Clueless.

Bw GJ

**Irritated GJ** August 2012

I'm fine with this. In all honesty I wonder if all this increased political correctness really leads to anything besides more noise.

It all boils down to how people act, not what they say.

Bw GJ

**Witty GJ** August 2014

Dear Stan

I gave the N paper an 'Almost reject' instead of a full one. In principle authors cannot be forbidden to submit anything, so there is little difference in practice, but I felt the topic per se might be of interest to EJHG. This hasn't to do with me being a coauthor, I'm just as fine with it getting published anywhere (I was with the discussion and they really wanted me in as an author) and we shouldn't cut papers any slack. But the reviewers considered this also of interest, were it not for all the chaos and rambling.

As an author, I'll give them an earful, and that is what should have done and DO blame myself for...

Bw GJ

**Witty GJ** April 2020

Hi Stan Thanks for enquiring. On a daily basis I'm doing fine. No Co19. Locked up in our fairly luxurious house where we can sit in the garden. 10 km outside Amsterdam, next to a nature reserve where we can walk the dogs.

My skirmish with prostate cancer is not going the right way however and I would not be amazed to need another chemo.

One can't win them all.

Like Woody Allen said: "No, shit doesn't happen! It takes a lot of work to make shit happen"

Bw GJ

**Thank you, GertJan. In your honour, EJHG signs off: "Sent from (too)smartphone. Sorry for typo's or unintended corrections."**