Memorial to Neil Kenneth Aaronson



By Monika Bullinger, Mogens Groenvold, Bob Kaplan, Madeleine King, Sandra Nolte, Bryce Reeve, Claire Snyder, Mirjam Sprangers, and Chema Valderas

> *"He was an influential fixture during ISOQOL's founding years, bridging cultures, languages, and methods. I will always carry fond memories of his wit, intellect, and friendship."*
> Bob Kaplan

Work Life, by Mirjam Sprangers

On September 2, 2026, Neil Aaronson died of cancer, two weeks before he would have turned 76. Neil was born in New York. He was trained as a behavioral scientist and obtained his PhD at the University of California, Los Angeles (UCLA) in 1983.

In 1984, Neil joined the then European Organisation for Research and Treatment of Cancer (EORTC) 'Quality of Life Study Group', as a postdoctoral fellow, working alternately in Amsterdam, The Netherlands, and at the EORTC Headquarters in Brussels, Belgium. In 1987, he was appointed psychosocial research coordinator at the Department of Psychosocial Research and Epidemiology of the Netherlands Cancer Institute in Amsterdam. Shortly thereafter he became head of the same department. In 1995, he was appointed Professor in Psychosocial Oncology at the Free University in Amsterdam, a position he exchanged in 2007 for a Professorship in Quality of Life in Chronic Diseases at the University of Amsterdam. He remained working at the Netherlands Cancer Institute until his official retirement in 2019. However, as a

dedicated researcher and tireless worker, he continued working until he was no longer physically able to do so.

His research at the Netherlands Cancer Institute focused mainly on three areas: assessing how individuals adjust to their illness and medical treatment; developing and validating standardized questionnaires for assessing quality of life of people with cancer; and developing and evaluating a range of behavioral interventions to enhance the physical and psychosocial well-being of people with cancer.

Neil had an international outlook and was one of the world's pioneers in research into the quality of life of people with cancer. He was one of the founding members of the EORTC QOL Group and played a crucial role in developing the widely used EORTC QLQ-C30 questionnaire. He was also a driving force behind many of its most influential achievements. He was the QOL Group's chair from 2005 to 2008. Neil was also among the early leaders of ISOQOL and held key roles, such as associate editor (1991-1998) and editor-in-chief (1999-2005) of *Quality of Life Research* and as president (2008-2009). He further participated as a member or chair in a wide range of international task forces, expert groups, committees, councils, advisory boards, editorial boards and review boards. Over the years, he emerged as one of the leading figures in the field and helped turn an innovative concept into an internationally recognized field of science. He received the International Psycho-Oncology Society, Bernard Fox Memorial Award for lifetime achievement in psycho-oncology research (2004) and the ISOQOL's President's award (2005).

Through his forward-thinking vision, scientific leadership, and dedication to methodological rigor, he played a pivotal role in establishing quality of life as an essential aspect of health care research. His legacy extends far beyond his own work, reflected in the patients who have benefited, the researchers and professionals he inspired, and the scientific community he helped foster.

Our hearts go out to Ineke, his wife, his daughters, Justine and Ilana, his step sons, Fabian and Vasco, their eight grandchildren, and all those who love him.

> *"A flood of memories has rushed through my head of the kindness, creativity, humor, and passion that Neil brought to the cancer research field, ISOQOL, and his personal relationships. He will forever be in our hearts and memories."*
> Bryce Reeve

ISOQOL President's In Memoriam, by Sandra Nolte

This is a slightly shortened text that was emailed to the ISOQOL membership on September 9, 2026:

"Dear friends and colleagues, dear ISOQOL community,

It is with deep sadness that we share with you that Past President Neil Aaronson passed away last week. It is difficult to imagine ISOQOL without Neil, who played such a central role in shaping our Society and our field as a whole.

Over the last several days in emails among the ISOQOL Advisory Council of Past Presidents and ISOQOL Board, the many tributes shared reveal not only the profound respect in which Neil was held, but also the extraordinary breadth of his influence. Through his scholarship, leadership, mentorship, and unwavering commitment to scientific excellence, he helped define the field and establish many of the standards that continue to guide our work today.

Neil's contributions to the science of patient-reported outcomes and quality of life research are immense. From his pioneering work in quality of life assessment in cancer clinical research dating back to the mid-to-late 1980s to his leadership within ISOQOL and his stewardship of *Quality of Life Research* as Editor-in-Chief from 1999–2005, he played a fundamental role in advancing methods, measurement, and application in the field. His work helped shape how patient experience and outcomes are understood, measured, and incorporated into research and clinical practice around the world.

As a leader, Neil brought exceptional intellectual clarity, strategic insight, and scientific integrity. He had a remarkable ability to identify the issues that mattered most, to ask the right questions, and to guide discussions toward thoughtful and productive conclusions. His influence was felt across disciplines, institutions, and continents, helping to bridge cultures, languages, and methodological traditions in the pursuit of better science.

One of Neil's most enduring legacies lies in his mentorship. Across several generations of researchers, he served as a trusted advisor, teacher, collaborator, and role model. He generously shared his time and expertise, offering thoughtful guidance, detailed feedback, and wise counsel to colleagues at every stage of their careers. Many of us benefited directly from his encouragement, his willingness to engage deeply with new ideas, and his commitment to helping others succeed. He exemplified the very best qualities of mentorship: generosity, curiosity, rigor, humility, and genuine investment in the development of others.

Several months ago, the ISOQOL Board received a proposal to establish the Neil Aaronson Excellence in Mentoring Award, submitted by Claire Snyder and colleagues. The proposal for the award received unanimous approval by the ISOQOL Board in late August, and plans were already underway to launch it at our upcoming conference in

Prague, where we had hoped to celebrate Neil and his contributions to mentorship, with him joining live by video or a video recording. While we are heartbroken that Neil will not be able to witness the launch, I am eternally grateful that we were able to share the news with him less than a week before he died. Neil's response reflected both his humility and the significance of the recognition: *"I am so deeply honored to have this award established in my name … I'm blown away by this."*

We mourn the loss of an exceptional scientist, mentor, leader, and friend. Our thoughts are especially with Neil's family. We hope they may find some comfort in knowing how deeply admired, respected, and loved he was by colleagues and friends throughout the world.

Warm regards,

Sandra Nolte, PhD
ISOQOL President"

> *"He truly was one of the towering figures (in more than one sense) of ISOQOL"*
> Chema Valderas

A Devoted Mentor, by Claire Snyder

Like so many of you reading this tribute, I was fortunate to benefit from Neil's guidance and counsel. His mentorship was far reaching, extending from colleagues at his home institutions to collaborators around the globe. He mentored students and trainees, junior and senior colleagues, researchers and clinicians. Some for a short period of time. Others, such as myself, for decades.

Neil served as a mentor to me in countless ways. Following a 2003 ISOQOL symposium he chaired on using PROs in clinical practice, I had the idea that we should have a special interest group (SIG) focused on that topic. At the time, SIGs did not exist in ISOQOL. I was still a PhD student and understood that this effort required someone with more experience and expertise than I had. I asked Neil to co-chair the initiative with me, and with the support of then ISOQOL President Albert Wu, Neil and I proceeded to recruit an organizing committee and form ISOQOL's first SIG. Based on these efforts, Neil and I later co-chaired a special conference in Budapest on using PROs in clinical practice, and the SIG developed the *ISOQOL User's Guide to Implementing Patient-Reported Outcomes Assessment in Clinical Practice*. While Neil offered his gravitas and shared his perspective, he provided me the opportunity to lead these efforts and shine.

As my own research agenda developed, Neil was always available to collaborate and contribute his wisdom and his wit. I had the opportunity to see Neil less than a month before he passed away. Even with everything he had going on, he was genuinely interested in how I was doing and how my research was progressing. Beyond our ISOQOL and research collaborations, I was honored and privileged to be Neil's friend. I owe so much to Neil for his support of our ISOQOL efforts, his scientific guidance, and his genuine care.

Which is why I am thrilled that the ISOQOL Board unanimously approved the creation of the Neil Aaronson Excellence in Mentoring Award. (Neil once told me I'm not allowed to say "thrilled," but I'm choosing to ignore his advice in this instance.) When I shared the possibility of this honor with him, he was "extremely flattered" and noted how "many deserving colleagues…would be eligible for such an award." By recognizing ISOQOL's many outstanding mentors, this award will serve as an enduring tribute to the man who was a devoted mentor and a dear friend to so many of us.

> *"I know no one who achieved such consistently high quality in research design, execution, and reporting. I also know no one who would tinker so ceaselessly with a text before being satisfied. But then again, I also know no one who writes so well. During meetings, he was usually busy editing manuscripts. Yet, he would unfailingly grasp the essence of the discussion and provide just the right turn to make everyone feel they were heading in the right direction again. His authority was beyond question."*
> Mirjam Sprangers

A Generous Colleague, by Madeleine King

I am saddened to hear of Neil's passing, but also rejoice in the rich and full life he lived. He was not only a wonderful mentor, but also a consummate role model of intellectual perspicacity and scientific integrity. In addition to his contributions to quality of life (QOL) measurement methods and instruments from the early years (1980s) via the EORTC QOL Group, and his contributions to ISOQOL's conferences and leadership, he made a huge contribution to our first journal, *Quality of Life Research*, as a magnificent editor-in-chief, including steering the journal through some difficult times and decisions.

My first connection with Neil was circa 1991 when I was starting my PhD about QOL in cancer, and I wrote to him about a new questionnaire, initially the QLQ-C36. He snail-mailed me a pre-publication hard-copy of what became the famous Aaronson et al. 1993 paper, with a hand-written note of encouragement and generosity. I went on to use the QLQ-C30 in my PhD project, and so began my long association with the EORTC QOL Group and ISOQOL. I had the privilege of working closely with Neil on ISOQOL's Executive in 2007-2008. As a leader, he was astute, strategic and fair. He was clear-minded and a very good communicator - a wonderful collaborator, including at write-up stage. And as I'm sure we all did, I had a lot of fun with Neil socially too. Who will ever forget his Tom Waits-ian renditions Minnie the Moocher at many an ISOQOL singing workshop?! It was my great pleasure to host Neil and Ineke in Sydney circa 2010. It was so lovely to see those two together. My thoughts now are with Ineke and all Neil's family members who will be feeling his loss so deeply.

> *"He was a unique person, with his earnest scientific mind and wonderful sense of humor"*
> Monika Bullinger

Leading by Example, Building a Collective, by Mogens Groenvold

For me, the sadness of Neil's passing has been accompanied by a pronounced feeling of gratitude. I am particularly grateful that in 2019, I had the opportunity to summarize and celebrate Neil's work and enormous importance to the success of the EORTC Quality of Life Group (QL) at his Farewell Symposium in Amsterdam. I used graphics to illustrate how Neil's leadership was instrumental in transforming what could be viewed as an amorphous landscape into a highly structured collaborative approach. In the following decades, this new model would inspire thousands of researchers to carry out the development, validation and application of numerous quality of life instruments based on a common, yet constantly evolving scientific strategy. Such a monumental effort is not achieved by just presenting the initial roadmap. It is an organic process, and we saw this at the semiannual QLG meetings across four or five decades, where Neil would always share his opinion aiming to 'raise the bar' of scientific thinking one small step at a time, while also being open to new perspectives. This inspired and contributed to the collective, while attracting new talent supporting the viability of the QLG.

Personally, I am particularly grateful for Neil's role as a mentor. When I made plans for my PhD about quality of life in patients with cancer in 1989, I felt a bit lonely working in a small country with no role models. Joining the EORTC QLG and experiencing the leadership and vision of Neil made an enormous difference, and I was so lucky that he

offered to help. I remember receiving his detailed comments even to the tenth draft of my first papers, explaining in the margins as well as in a long accompanying letter how we might be approaching something publishable. For many years, he helped me generously in developing my scientific thinking. I knew that my arguments in new projects or manuscripts would be carefully tested. Working with Neil strongly inspired my subsequent work and career and not least my experience of the joy of trying to contribute to the advancement of science.