

# Accomplishments of Heinz Baumberger PhD: a remarkable patient with ankylosing spondylitis for 72 years

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**Abstract** This is the story of a remarkable Swiss patient—Heinz Baumberger, PhD—who was born in 1931 and has suffered from ankylosing spondylitis (AS) since 1943. He has survived many manifestations and co-morbid conditions associated with his disease and its treatment. These include severe episodes of acute anterior uveitis, osteoporosis with fragility fractures, and also post-traumatic spinal fractures on three different occasions. In addition, he has suffered from multiple basal cell carcinomas as a late complication of a 3-week course of spinal radiation in 1952 and another one in 1962. It was only in 1971 that Dr. Baumberger for the first time met a fellow sufferer from AS, and he subsequently helped establish the Swiss AS patient support group, the second such national group in the world. He co-authored with his rheumatologist an excellent and well-illustrated book on AS for patients and their family members and for allied healthcare professionals. He travelled extensively around the globe lecturing and participating in various meetings and congresses in his zeal to spread the idea of self-help organizations for patients with AS.

**Keywords** Ankylosing spondylitis · Axial spondyloarthritis · Bamboo spine · Basal cell carcinoma · Fibroepithelioma Pinkus · HLA-B27 · Juvenile onset · Morbus Bechterew · Osteoporosis · Schweizerische Vereinigung Morbus Bechterew · Spinal fractures · Spinal irradiation · Spondyloarthropathies · SVMB · Uveitis

This is the story of a remarkable Swiss patient—Heinz Baumberger, PhD—who was born on December 30, 1931 and has suffered from ankylosing spondylitis (AS) since age 12, a disease that is more commonly known as Morbus Bechterew in German-speaking countries. His clinical history and his accomplishments against all odds are very instructive and educational not only for patients and their families but also for rheumatologists and other individuals interested in AS. He has faced many manifestations and co-morbid conditions associated with his disease and its treatment. These include severe episodes of acute anterior uveitis, osteoporosis with fragility fractures, and also post-traumatic spinal fractures on three different occasions. In addition, he has suffered from multiple basal cell carcinomas on his back as a late complication of two 3-week courses of spinal radiation, one in 1952 and the other in 1962.

His symptoms began in 1943 when he was 12 years old, and by the time he reached high school, he had already developed impairment of his spinal mobility so that he was unable to join in his school gymnastics or play with his friends or do skiing. He recalls a dreadful experience in 1948 at age 17 when he was subjected to a 3-week course of physical therapy at a rheumatism spa center. His disease was finally diagnosed in December 1951 at age 20 by a rheumatologist and was subsequently treated with a 3-week course of spinal radiation, the only treatment available those days that used to provide some benefit for this disease. He was by that time working as a teacher at a grammar school, and was called up for military training service but was not accepted because of his AS. Not to do military service was a serious handicap in Switzerland in those days, especially when applying for a job. Moreover, he had to pay a higher premium for life insurance, and his health insurance wrote in a proviso restricting the benefits payable because of his AS. In addition, he was not accepted for the “staff provident fund,” which meant that in the event of sickness or accident, he and his parents were left without protection, security, or income.

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By the time he was married in 1957, his symptoms had rapidly worsened, resulting in another admission to a hospital for rheumatic diseases. He returned back home as a “mental and physical wreck” because of worsening back pain and stiffness; he needed his wife’s help in washing, dressing, and even getting into and out of his bed. Within 20 years after his diagnosis, mobility of his whole spine was markedly impaired, including his neck. He received a second 3-week course of spinal radiation in 1962 that brought a certain degree of relief but it greatly undermined his general health. He continued his job as a school teacher and, in addition, he started taking classes at a university in his spare time. It took him 9 years to obtain his PhD in biology [1]. But this double burden over those years had sapped his health almost to a breaking point, and his wife and two daughters had been through very hard times.

He suffers from primary AS, without any associated psoriasis or inflammatory bowel disease. None of his immediate family members have AS or related types of spondyloarthritis. He does possess HLA-B27. He has had many episodes of acute anterior uveitis; the last episode was very severe and was associated with macular edema. He has had fragility fractures of wrist and lower leg due to osteoporosis related to his AS. He also suffers from mild to moderate obstructive sleep apnea.

The gradual availability of more effective anti-rheumatic therapy brought him a welcome relief and helped him to increase his mobility to some extent, although his whole spine had become stiff, his breathing restricted and his muscles weak. He was finally able to sleep better after about 15 years of not having had a proper night’s sleep. He also gradually overcame his resistance to physical therapy, including spa treatment. At first, physical therapy merely made matters worse and only gradually did he become aware of small improvements. From that time point, he regularly went for 4 weeks of intensive physical and spa treatment and water therapy every year. The pain in his back, chest, and neck finally abated after 35 years of the disease, and he started enjoying this new lease of life.

It was in 1971 that Dr. Baumberger for the first time met someone else who had AS. It was great help to him to hear from this patient and subsequently from many other patients about their experiences with this disease. As a result of such conversations, an idea was conceived by him to start a patient support group to educate, support, and help each other. This finally led to the formation of such a group in 1977 by him and three other patients, and a year later, 155 individuals attended the first meeting of the “Schweizerische Vereinigung Morbus Bechterew” (SVMB) or the Swiss Ankylosing Spondylitis Association in English [2]. The association members later found out that their’s was the second such AS patient support group in the world, only preceded by the National Ankylosing Spondylitis Society (NASS) in England.

As president of the SVMB from its inception till 1992, Dr. Baumberger played a major role in establishing local self-help groups all over Switzerland in collaboration with the physicians, physiotherapists, and hospitals [2–5]. It is a very active patient self-help organization with more than 4000 members, and it has been organizing local group meetings and lectures, as well as group exercises (including aquatic exercises) that are run by trained physical therapists. It also organizes an Annual Swiss Ankylosing Spondylitis Congress, and at the very first such congress in 1979, Dr. Baumberger invited participants from Germany, and this subsequently led to the establishment of similar AS patient self-help societies in Germany and Austria.

The Swiss association web site provides useful information for AS patients and their families, as well as to healthcare providers [2]. In addition, the association provides printed brochures on all aspects of AS because anyone suffering from a disease that afflicts during prime of one’s life would like to know more about the probable course the disease will take, the degree of physical impairment and disability to be expected over the years, the necessary treatments, and everything connected with the work and social environment. The association also brings out a quarterly bulletin called “Vertical” that contains articles on these and other subjects of importance to the patients and healthcare providers [2]. Moreover, it provides general information to the public and the media, and also supports medical research in AS.

Dr. Baumberger, along with delegates from 11 other national organizations met in Bath, England, in 1988 to establish Ankylosing Spondylitis International Federation (ASIF). A year later, he hosted the inaugural ceremony of the founding of ASIF, along with its first international meeting, on July 8, 1989, in Leukerbad, a famous spa center in Switzerland [6]. It attracted delegates from 17 countries, and I was the delegate from USA. It is encouraging to know that ASIF now represents 37 national organizations from 35 countries on all 4 continents ([www.asif.info/en](http://www.asif.info/en)). He has made more than 45 trips abroad lecturing and participating in various meetings and congresses in Europe, Asia, and Americas in his zeal to spread the idea of self-help organizations for patients with AS [7–14].

Dr. Baumberger has post-traumatic spinal fractures on three different occasions; the first occurred in April 1981 at age 50 when he fell on ski slopes and slid 200 m downhill and was airlifted by helicopter. The fall resulted in multiple rib fractures (7th to 11th ribs on the left and 8th right rib) along with bilateral hemothorax, ruptured diaphragm, contusion of his entire spine and pelvis, and fractured nose. He had also suffered compression fractures of his lower two thoracic vertebral bodies (primarily T10), but it took more than 5 weeks of hospital stay before clear visualization of those fractures was obtained. The earlier radiographs had not revealed these compression fractures as they were

obscured by bilateral hemothorax, and the clinically worsened kyphosis (30° angle) had wrongly been presumed to just be due to his AS.

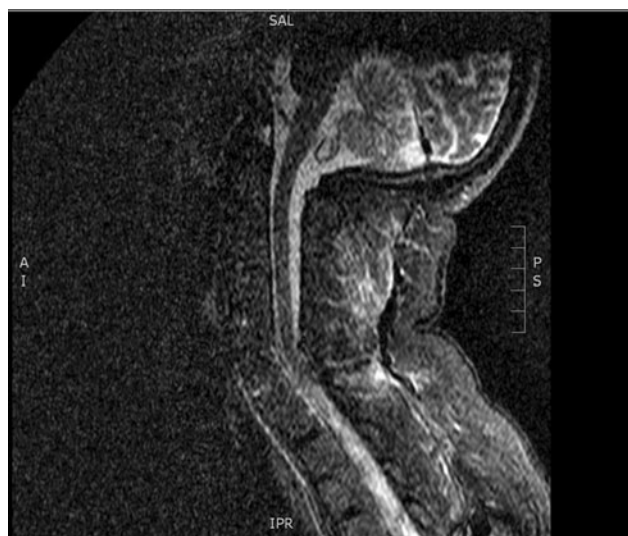
His second spinal fracture occurred in December 1993 at age 62 when he slipped on a snow-covered road that caused a transdiscal fracture between T8 and T9. It subsequently resulted in pseudoarthrosis that needed surgical fusion along with correction of his previous thoracic hyperkyphosis that had resulted from his first spinal fracture. It took 8 h to perform osteotomy at T10 and spinal fusion from T5 to L2 by using metal plates and screws. He regained 10 cm in height after the surgery, and this also relieved him from his cardio-respiratory compromise that had resulted from his marked kyphosis.

In 2012, he failed to see a step as he was exiting a store and fell forward with full force on to the sidewalk. He was hospitalized due to craniocerebral trauma with severe brain concussion, broken tooth, and contusions of the frontal bone, upper lip, left shoulder, and left wrist. On examination of his body for further injuries, possible cancerous skin lesions were noted on his lower back, and resection was recommended because of his past history of X-ray irradiation treatment that he had received for his AS in 1952 and 1962.

In September 2012, three histologically confirmed cutaneous basal cell carcinomas were removed from his lower back, a well-known delayed complication of the radiation treatment had received many years ago [15–18]. He has no other known risk factors for cutaneous malignancy. Two months later, six additional histologically confirmed superficial basal cell carcinomas and a fibroepithelioma Pinkus were excised [19]. It was difficult to suture the skin back together because of extensive subcutaneous fibrosis, and resulted in infection and recurrent abscesses that were repeatedly drained. He was later hospitalized with septicemia, and after 3 weeks of antibiotic therapy, he was transferred to a rehabilitation center.

His most recent spinal fracture happened 2 days later in the rehabilitation center when, after celebrating Christmas night with his wife, he mistook the edge of the bed and fell backwards, hitting back of his neck on the edge of the night table [20]. He was transferred back to the hospital into the same bed he had left 2 days earlier. MRI revealed extension fracture of his lower cervical spine (between C7 and T1) (Fig. 1), On New Year's Eve, Dr. Kan Min, a young renowned spine surgeon, operated for 4 h and successfully fused the fracture with rods and screws without any complications (Fig. 2) [15]. But the skin infection that had resulted from his previous resections of basal cell carcinoma lesions required multiple drainage of abscesses and repeated courses of antibiotic therapy [15]. It took 9 months (from November 2012 to July 2013) for the skin to finally heal.

Although Dr. Baumberger is not a physician, he worked hard to gain extensive knowledge about AS and co-authored with his rheumatologist an excellent and well-illustrated book



**Fig. 1** MRI of cervical spine. Lateral view showing spinal fracture between C7 and T1 vertebral bodies

on AS for patients and their family members, as well as for allied healthcare professionals [21]. His knowledge about the occurrence of spinal fractures in AS and how medical emergency services should handle such patients with presumed spinal fractures was very instrumental in preventing spinal cord damage after each of his three spinal fractures. He and his wife always made the paramedic and other healthcare providers aware that he suffers from AS, and requested not to put



**Fig. 2** X-ray of thoracic and lumbar spine (*lateral view*) showing surgical fusion of his relatively recent spinal fracture between C7 and T1 vertebral bodies. The X-ray also partly shows his previous spinal osteotomy at T10 and fusion from T5 to L2 by metal plates and screws



him on a stretcher, and demanded a special scoop stretcher and a vacuum mattress. If he had to be transported on a regular stretcher, he would lie down on his side to minimize risk of stable spinal fracture becoming unstable.

Dr. Baumberger is truly a role model for all of us, having faced with courage and perseverance all these hurdles posed by his AS, and went on to help others. He is still enjoying life fully with his very supporting wife (they have been married for 59 years), and their two daughters and two grandsons. I recall my first meeting with him in 1983 in London, England, after my lecture at an international scientific meeting on HLA-B27. I told him that I too have been suffering from HLA-B27(+) primary AS since age 12 [22, 23, 24], but I did not tell him that just a day earlier I had sustained a cervical spinal fracture and I was flying back home for treatment.

Two years ago, I travelled to Zurich after his 83rd birthday and found him to be full of life and always optimistic. Typical of his hospitality, he invited me for a very nice dinner with his wife and two daughters, and the next day took me to the office of SVMB and arranged a lunch with its office bearers at the historic VIP dining hall at top of the tower of the University of Zurich, his alma mater (Fig. 3). He also took me to a group exercise session for AS patients organized by SVMB, and visited the hospital where he had received most of his care, and met its faculty, including Dr. Kan Min. We later took a train ride to Berne to attend the annual meeting of the Swiss Society of Rheumatologists, and I was pleased to know that Dr. Baumberger is an Honorary Member of this Society in recognition of his great accomplishments.



**Fig. 3** Dr. Heinz Baumberger (*left side* of the picture) with the author (Muhammad Asim Khan) at the balcony outside the historic VIP dining hall at top of the tower of the University of Zurich, his alma mater

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