

In Memory o

A Personal Tribute by Jeremy Manuel OBE

When I told David, Susan's husband, that I wanted to add a personal tribute to Susan in Gauchers News he told me that I had to keep it short as Susan did not want to be "canonised" after her death. He said that Susan had said she would only want the minimum of fuss made and that we should not be saddened by her passing.

I should have expected this because it is characteristic of Susan's humility and modesty but it gave me a real dilemma because I had so much to say about Susan from the 15 years of us working together. There are countless stories to tell, incidents to recount but the restriction forced me to focus not on Susan's achievements through the Association but on the essence of our professional and personal relationship.

The fact that Susan was super efficient, highly organised, a stickler for detail, demanding the best of herself at all times (and delivering it) is well known. Her journalistic background meant that she was rarely seen without her notepad jotting down information and action points. It was these skills that got the Association off the ground, collecting information, raising the profile, making contacts and disseminating it all for newly identified patients. But for Susan this was not just a process it became a mission. She worried about individuals, she learned their names, details of family members, medical circumstances and she would often call me to discuss a particular case. She was anxious not to offend or tread on toes and was determined for each and every individual to find the best course of action. I rarely saw her angry but when she was it was only because she had perceived injustice on behalf of a deserving patient. In the early days when health authorities would deny treatment arguing it was experimental and latterly when she feared the potential impact of the NICE review on access to expensive treatments for Gauchers patients and those with other LSD's she was stirred into passionate action.

This always led her to giving of herself. In many ways a very private person she was willing to bear her own story because she felt she had to – to protect treatment and to secure the future for others. I accompanied her to the presentation she made to the Citizen's Council of NICE when they were carrying out their review of treatments for ultra orphan diseases using Gaucher Disease as the model. I know how hard it was for her to make this presentation. It went against her natural instinct to respond to every enquiry of her health with "I'm okay" for her to publicly recount the painful and life threatening incidents in her life but she knew she had to do this for others.

And what was it like to work with her? The answer is that together we went through the full range of motions. At times it was challenging – we would brainstorm and devise strategies for action, the best way to present our case to authorities, public bodies, and industry; it could be unbearably sad and urgent when trying to help cases of very

ill people both in the UK and overseas: it could be elating when hearing that a patient had finally received treatment; it could be heart warming and inspirational when hearing of selfless acts of kindness of members and their friends and it could (and perhaps this sounds strange bearing in mind the subject matter of many of our discussions) be fun. Susan had a great sense of humour and if something made her giggle all around her would share the laugh.

We became a team working together almost intuitively, but Susan took the great burden of the work on herself. We would constantly talk. We joked that if we did not speak at least four times a day one of us had to be away and our conversations often strayed from Gauchers matters. I certainly enjoyed the intellectual debate that often flowed. We did not always agree but we respected each other's viewpoint.

From the time of the formation of the Gauchers Association until July 2005 we did everything together and when she told me that she intended to retire on her 60th birthday I knew that I could not dissuade her. With other executive members we set about the task of restructuring the Association so that we would be able to continue as we had done before. Susan told me on more than one occasion how delighted she was with the way Tanya had filled the gap. Although we no longer spoke so often as four times a day she was always available to give help and advice.

Susan was interested in people. She was concerned and cared for them and there are countless individuals in the UK and overseas who have benefited from that concern. I miss our chats, the pride with which she spoke of her sons, her niece and nephew and great niece and great nephews and her genuine delight when hearing of my children's achievements.

Susan was physically small and slight in stature but huge in personality and achievement. She was modest of the impact of her work, sometimes incredulous that "little me" as she would describe herself was standing up to Ministers of State, captains of industry or challenging learned Professors.

Professor Cox has said that she was an exemplar of the maxim of turning "private pain into public gain" and indeed the Gauchers world is a better place for Susan having lived (albeit for too short a time) in it.

We all will miss her, I will miss her clear thinking and focus on what needed to be done, her judgment, her sparkle, her concern, our debates and her advice. Most of all I will miss her friendship and her personal kindness. It has been my good fortune to have known her and to have shared so many experiences with her.

On behalf of all members and friends I send condolences to David, to her sons Duncan and Matthew and to her sister Ellen and my hope that the outpouring of affection and great esteem from around the world that has followed her death is a source of comfort to them.

Susan Lewis



A Letter to Susan Lewis (from Joan Grantham)

Susan, this is strange. I am sitting down to write about you on one of your days - bright sunshine, blue skies and just a tiny breeze, and my first thought is 'I'll ring Susan to see what she thinks'. That's how it is without you now. The phone calls have stopped. The smile - always the smile - is in my mind's eye only. The voice 'Hello Joan, it's Susan here - how are you?' is in my head, everyday without fail, and it is all so tangible that I feel somehow you are not gone. That I will still go to King's Cross and get in your car so we can have lunch. Gin and tonic and olives for me first, kindly provided by David, under a tree in your Hampstead garden. And then, Susan, your lists of all that needed to be discussed and dealt with that day. And much was achieved - under such circumstances how could it not?

So much has been written since your death. I thought of adding to these words with a catalogue of things that we accomplished through our offices. But brevity is best. We spoke about patient issues, funding, political issues and fundraising matters with the charity dinners in College, auction of paintings and a musical afternoon and you were always there ready to help and listen. Time was not kind to you Susan and I always felt you knew it would not be, but you still gave your time freely and with such good grace.

When you rang the office you would often say that you needed to speak to Prof but you wanted my opinion first. When I gave it you always listened carefully. That's the kind of friend you always were - loyal, kind and thoughtful.

In the last winter months, when you were so ill, you wished that the sun would shine and that we could sit under a tree. You asked me to promise that in July on a visit to Seattle for my son's wedding, we raise a glass of champagne and drink to you on your birthday in the sunshine. On my visit to you in April, with Ellen and David's kind help, you spoke to me of Seattle again; you were so poorly that day but still concerned. On 14th July, Susan, the sun will shine and we will drink to you and remember you on that day of double celebration.

Thank you for everything: the thoughtfulness, the humour, the fun and most of all the friendship.

Sleep well, Susan, sleep well.

Below are extracts from numerous letters and cards received by the association and Susan's family following her death;

I feel honoured to have had the privilege of meeting Susan. When I think of Susan all I can remember is her smile which will remain with me forever.

Naheed Qureshi

I first spoke to your wife 2 years ago when our son was un-expectantly diagnosed with Gauchers disease. Susan was very kind and helpful to us, being very positive about Joseph's care and treatment that he would receive. I will always be grateful to her for answering all my questions and being reassuring.

Susan Yarrow

I was so sorry to hear the news about Susan. She was a wonderful woman who, almost single handedly put Gauchers disease on the map in the UK. She was the first person I ever spoke to who had the same disease as I did and her calm, good sense was so reassuring for me. I know I am not the only person who has a great deal to thank Susan for.

Anne Begg MP

I have such fond memories of a courageous lady, strong yet small, and with an ever present smile! She was always ready to listen, and never pre-judging, but had a sharp mind. Her care for other Gaucher patients, their families and relatives was legendary. Funny, but now that I reflect, she seldom made any reference to her own condition, instead focusing on this or that Gauchers Association issue, what a selfless lady.

Dr. Paul Schofield.

Susan was an inspiration to us all. She changed my life. She changed the lives of my husband and our five children. Without her hard work with the Gauchers association I would never have known of Cerezyme treatment and therefore would never known "normal" health as I do today. I will always be eternally grateful for all her help and encouragement.

May she rest in peace.

Susan Cowan

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Susan made so much difference to my life and the lives of so many others. She will be remembered in my heart always.

Evelyn Ashdown

She was a great woman, with a great soul, a sense of humour and intelligent; a sensitive woman, who was always ready to help. Her laugh and smile cannot be forgotten.

**Prof Mia Horowitz,
Tel Aviv University, Israel**

You will all be feeling this loss-such a lovely, gentle and courageous lady, whose smile was never far away.

Lesley Greene, CLIMB

She did so much to make society aware of the disease and fought for treatment. She will be greatly missed. It was her visit to my office in the late 80's or very early 90's that instigated my own involvement with research on Gaucher disease.

Professor Bryan Winchester

Susan was such a special person and I had the utmost regard and respect for her. She accomplished so much for the entire Gaucher community around the world.

**Rhonda Byers,
National Gaucher Foundation, USA**

Susan has been not only for me a partner in this journey we undertook in Gaucher disease many years. She was more. With her delicate yet assertive way of describing her illness and the hopes after the coming of the enzyme replacement therapy, she has definitively inspired my job at Genzyme. With others like Ria, Fern, Robin in the US and many more, I consider Susan as an integral part of the success of transforming Gaucher disease into a treatable illness.

They say that "the show must go on", however our "Gaucher world" will not be the same without Susan.

Carlo Incerti, Genzyme Therapeutics

I share in our collective sadness in the Gaucher community throughout the world. Susan was an inspiration and what she exemplified was precious. She had vision

that was very evident when I first met her in 1991 in Amsterdam and courage that few of us can match. Her wisdom in all matters, whether, public policy, advocacy or politics was transcendental and always with the singular goal of improving the lives of people affected by Gaucher disease not just in UK but throughout the world. It was an enormous privilege to know Susan, to be inspired by her and guided by her extraordinary wisdom. Her memory will for me and many others, be a lasting source of inspiration.

**Professor Pramod Mistry,
Yale University School of Medicine**

Susan has been for me a friend, a guide and in a way also a role model. I will miss her a lot. We all owe her many of our achievements in the struggle for the patients.

It was an honor for me to know her, to work with her and to share with her very difficult moments connected to our common "interest": Gaucher disease.

**Dr Raul Chertkoff,
Medical Director, Protalix Biotherapeutics
(Former Chairman of the Israeli Gaucher
Association)**

I was saddened to hear that Susan Lewis passed away. She was a warm, compassionate, and remarkable woman who accomplished much on behalf of the world-wide Gaucher Community.

Few have done as much for us as she did. I feel privileged to have known Susan and will miss her.

Sam Shponka, U.S.A.

We are cognisant of the enormous contribution she made for the patients with Gaucher disease, not only in the UK but world-wide. She was of great help to our society on many an occasion and indeed the British society has been a role model for ours and thus we are greatly indebted to her.

May I wish you all a long life and may you be spared any further sorrow.

**Hylton Sevitz,
South African Gauchers Association.**

Susan was a role model of fight, tenacity and devotion for all the patients with Gaucher.

She was a sensitive, generous person who

cared about all the patients and for us, the ones from Romania; she was a real support through many of the problems we encountered over the years.

She was not only enthusiastic and energetic, but also deeply caring which is shown by her tireless work on behalf of the Gaucher patients.

**George Sinca,
Romanian Gauchers Association**

Her generosity and dedication to others as well as her struggle for helping sufferers of gaucher disease will always be remembered. All members of the Israeli Gauchers Association send their thoughts and prayers to Susan's family and all the members of the UK Gauchers Association at this difficult time.

**Yossi Cohen,
Chairman of the Israeli Gauchers
Association**

I am sure that her spirit will remain with us, with her distinguished personality, human character and ability to give what ever she can for any human being, I am personally learned many things from her, she was with Fernanda who motivate me to do our JGA, so not me only but all JGA members, patients and families feel so sorry for her absence, we will continue what she started, she will be always with us.

**Dr Mohammed Antaki,
Chairman of the Jordanian Gaucher
Association**

Susan was a beacon of optimism and humanitarianism and loving kindness.

She will be sorely missed, by the people who knew her intimately, and also by those who knew of her compassion and good deeds.

She will be missed by those who only knew her by reputation as the one person in an impersonal system, who would always find time to listen and a way to be helpful.

Susan has a great lady who never let her personal issues de-rail her from her main purpose, and that was always, caring for her fellow patient.

We will always view any compassionate therapy program in the world of lysosomal diseases as a personal tribute to Susan, because Susan was the pioneer to champion the cause of treatment for all who need it.

**Prof Ari Zimran and Dr Debby Elstein,
Shaare Zedek Medical Centre, Israel**