



## MARROW MATCHING MARRED BY CLASHING EGOS

A three-way territorial struggle between two fund-raisers and the South African Bone Marrow Registry (SABMR) over maintaining and updating the donor register is allegedly preventing the optimal recruitment and tracing of life-saving bone marrow donors.

The longstanding spat between a handful of senior clinicians who are officials of the SABMR, and the Sunflower Fund (SF), a high-profile fund-raising NGO (a seminal Gauteng-based one recently gave up 'in disgust'), centres on claims of 'turf protection' and 'madcap bureaucracy'. The main bone of contention is the lack of transparency around the bone marrow register, located on a computer in the Tissue Immunology Department at the University of Cape Town's Falmouth Building.

However, a history of 'north-south' territorial jealousy between the two main fund-raising NGOs, in spite of several SF-led attempts to unify, has aggravated matters. One angry SF board member reportedly suggested 'pulling the fund-raiser carpet' from under the SABMR, having it forensically audited and a probe conducted to see if it meets its ethical and legal obligations around human organ donation. He also reportedly suggested that the registry be 'kicked off' the UCT campus.

Repeated requests by the SF to be allowed to update the data linked to 59 000 donor names have been met with 'unwillingness and reluctance' by the SABMR, whose board has no fund-raiser representation. Allegedly viewed as a 'group of hysterical housewives' bent on interfering with the scientific projects run by the senior academics and top clinicians who jealously guard the registry, the SF believes it could eliminate duplication, update personal details of donors and increase the number of multiple-use donors, thus enabling quicker matches.

'They (the SABMR) have no idea whether the donors are still alive or even willing,' charged one SF source. The SABMR strongly denies this and claims legal constraints around patient confidentiality and medical ethics are

responsible for its reluctance to release the data, most of which were garnered by their fund-raisers. It points to the register being '95% white' as a priority for demographically representative donor recruitment and believes the SF is off-beam when it comes to priorities.

### Fobbed off

SF founder Tina Botha, whose artist son Chris died of leukaemia in 1997, told *Izindaba* 'They keep telling us they'll table our complaint at their next board meeting or that the information is medical and confidential – but the joke is that we recruit the donors! We know the agony of waiting in hope and merely want to give all blood disorder sufferers their best shot at success.'

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Botha believes that the donor list is badly in need of 'freshening up' with information about the donors' current status (deaths, pregnancies, new or changed medications, etc.). 'The bottom line is it's slowing delivery down. We could get things going quicker,' says the former nurse and sales and marketing manager whose publicity campaigns (e.g. the Bandana Campaign) have helped boost the register from 1 000 to 59 000 names in just 6 years.

Says Botha, 'If you have a great registry, you have a chance of life', adding that annual donor newsletters and registry upkeep were common practice in Australia and the UK. The SF raised R1.9 million for tissue testing last year alone and helped change bone marrow transplantation from 'relatives-only' operations (prior to 1998) to tissue typing internationally with a dedicated call centre that expands during major publicity campaigns. The SF claims that prior to this, callers were sometimes

faced with the Falmouth laboratory's answering machine.

### Gauteng's silent pull-out

The Gauteng-based Darren Serebro Bone Marrow for Africa Foundation, begun by Mervyn Serebro, father of the 23-year-old leukaemia victim, 2 years prior to the Cape Town-based SF, threw in the towel 4 months ago after failed merger talks with the SF.

Serebro's NGO added 26 000 names to the database, helped start up the Cape Town-based SF and piloted free blood and tissue sampling by Gauteng's 30 National Blood Transfusion Centres. Serebro declined to elaborate on reasons for his NGO's pullout, referring *Izindaba* to Professor Ernette du Toit, the medical director of the registry and head of UCT's Tissue Immunology Laboratory.

Du Toit scoffed at the registry data being 'sub-optimal', saying their failure rate for finding a listed donor stood at 1%, which was 'no higher than any other register internationally'. By putting an age ceiling for donors at 55, she said the SABMR was able to update for increased mortality, although she conceded this was the only attrition measure in place.

'If you're a perfect match we try and contact you, whether you're there or not,' she said.

She emphasised that about 95% of their donors were white and that most patients found donors from overseas registries, while 25% found donors in their immediate siblings, with 5% finding donors from relatives in their extended family (parents included).

### Facts and figures

Du Toit, who began the registry with haematologist at Constantiaberg MediClinic, Professor Peter Jacobs, said 25 of the 86 patients who had undergone bone marrow transplants in South Africa since 1997 had received donations from their compatriots. The overall long-term survival rate was 'about 50%'.

Du Toit said the chances of finding a match for any patient in the South African registry was 'about 1 in 100 000'.



Sunflower Fund workers; Venessa Horn; PR Manager Cape Town, Tina Botha; CEO, Pippa Hunt; PR Manager Gauteng, and Bhavanisha Chanderparsadh; PR Manager KZN.

She confirmed tensions between the SF and Serebro in Gauteng, saying it seemed to revolve around the SF's popular and well-known sunflower logo and the lack of a joint fund-raising body and mutually acceptable branding. (The SF logo was taken from a painting of a sunflower by Tina Botha's late son, Chris.)

'It's simply not true that this is affecting the availability of donors – yes, some energy has been lost in recruiting but the data are not sub-optimal,' she said, adding that the registry was registered with the world bone marrow association and regularly inspected. 'We're hosting the next international meeting for bone registries in Cape Town this year (2006) – they wouldn't have chosen us if we were below par,' she added.

The SABMR wants Botha's SF to first update a list of 8 000 potential donors in KwaZulu-Natal who were recruited 'years back' without being told what the information was to be used for.

Du Toit confirmed resisting repeated attempts by the SF to create a regular newsletter and cards of acknowledgment to potential donors (on the registry), saying it was too costly.

The registry was begun in 1991 after Jacobs and Du Toit were warned by international colleagues that they would struggle to trace unrelated donors

globally without first creating a local registry. Du Toit said that instead of 'spending funds', the SABMR wanted the SF to prioritise the recruitment of black donors, a major demographic failing of the current register. Mrs Terri Schlapoff, deputy director of the SABMR, told *Izindaba* that Botha did not have the medical expertise to type donors beyond the AB classification.

'We say that our database could be better if there was more black recruitment,' she added. 'The SF has set themselves up to provide assistance to us, which we're not unhappy about, but we'd hoped for more black recruitment. I wouldn't say the SF resisted this but it hasn't been a solid focus,' she said.

Du Toit added, 'One of my big beefs is that the registry is mostly white. The recruiters have gone to easy targets like shopping centres in Constantia – it's not so easy to go to Gugulethu. Tina wants to get her hands on the data – she has other things to do, like educate people in the townships.'

#### No agreed-upon strategy

Botha said the SF had pursued the issue of black donors and increasing level 2 (HLA DR) donors with the registry shortly after their AGM this year but was told that updating the KwaZulu-Natal

donor cohort and sending out vouchers for level 2 tests were priorities.

The SF began collaborating early in October with the SA National Blood Transfusion Service to identify regular black blood donors so they could be asked to also donate bone marrow stem cells and regularly used high-profile black celebrities in appeals to address the shortfall.

Botha described the shortage of black donors as a 'clever red herring' to the main issue of the SF wanting an overall agreed-upon plan 'about the way forward'.

#### Ignition point

Matters reached boiling point in early November when an attachment to an e-mail from Du Toit to her board chairman, Professor Francois Retief, in which she claimed to be 'fast going grey from all Tina's letters' and spoke of 'concocting a letter' to try and pacify her, was inadvertently copied to the SF. This so incensed SF board chairperson Dr Nicholas Crisp, notified while doing consultation work in Nigeria that he fired off an angry e-mail to his SABMR counterpart, threatening to take the SABMR to the Minister of Health for investigation.

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The estrangement among the vital players extends to bickering about 'free tables' for pathology laboratories at the well-known SF-organised annual Mount Nelson Hotel charity ball and auction in Cape Town, where tickets cost R650 per person. Several major pathology laboratories provide free testing and transport services to the SABMR, whose executive wanted to 'reward' them. However, Botha says even her own staff and SABMR staff pay for tickets to attend.

**Chris Bateman**