

THE SUM OF US

Collective reflections on a remarkable woman, Levinia Crooks AM

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Responding to the public health dilemmas that face us requires collaboration between community, pharmaceutical, NGOs, and medical groups and we all have a role to play – some take a leading part, others play a supporting role. Some seek the limelight, others are happy to stay in the background.

If you are living with HIV, hepatitis or a blood-borne virus, live in a community affected by these conditions, or have worked in the blood borne virus sector in Australia, you have been touched by the efforts of Levinia Crooks.

And you may be aware that you are no doubt part of a generation of health professionals in our sector right across Australasia who have been formed by the relentless and tirelessness efforts of a single woman, pushing for significant, meaningful and often dramatic changes and improvements in the responses to HIV, sexual health and viral hepatitis.

Whether you knew her, knew of her, passed her in the hallways of some conference, sat with her in some meeting somewhere or read one of the copious volumes of policies, practice guides, funding submissions, strategies, reports or opinion pieces she authored, Levinia's fingerprints, along with her tenacity, her passion and her perseverance remain in the record as a legacy as one of the architects of the response to HIV in Australia.

Some of us stood with her when we were angry and scared. Together we crafted the slogans that we put down on placards, we organised countless letter writing campaigns and we walked together down the street holding candles, reading out the names while holding back the tears. Together we persevered.

Some of us spend many a late night trying to penetrate the vernacular of pharmaceuticals, the weird code of virology, or the cut and thrust of scientific enquiry and debate. We strove to match her dedication, resolve, energy and sheer determination to ensure change for any number of countless initiatives she championed.

Some of us danced with her, rolling our heads to the music, eyes closed, we lifted our arms to the delights that lifted our spirits.

Some of us felt her fury; others saw it on show. She had command of the vernacular that would make a sailor blush and she passionate about tacking the hard tasks and issues that others just talked about, or blatantly ignored.

Some of us, as her students, saw her in full flight during lectures. It was more than teaching; she inspired us to reach further for the possibilities of the action that would make meaning of what



she had to say. She pushed us harder and further than we thought we could go.

Some of us felt her compassion, maybe directly when she offered an opportunity that otherwise we wouldn't have had or when she took time from her constantly busy schedule to help us understand what we were doing. Certainly for those of us who are often considered to be 'marginal' (the positive injecting drug using poofster sex worker), she stepped up and out in front and demanded that all of us leave our misconceptions, prejudices and our bigotry at the door.

Some of us watched in awe as she took charge of the ubiquitous white board covered in thoughts, comments, contradictions and collaboration. And as if by magic, through what seemed like an incomprehensible mess, brought disparate thoughts into a comprehensive project statement and plan of action.

Some of us ended up on her lounge room floor travelling from interstate for an ACT UP action or Mardi Gras, and were greeted by Levinia in her trademark black leather vest and Doc Martens. She knew the power of how to harness a community which didn't just reside in bricks and mortar of an organisation, but was felt just as viscerally in the bars and on the streets.

Some of us are part of that special group of people, nurtured and cultivated for our caring and compassionate nature. A rag-tag assortment of professionals across Australia speaking out for the people that we care for in different communities. And beside us, supporting us, a dedicated, strong and brilliant team of people who have travelled through the ranks at ASHM.

Some of us saw through the 'tough guy' image to a core of warmth, generosity, care and absolute dedication to the rights of those she ultimately served. We saw the wounds if those core values were ignored, questioned, unacknowledged, misattributed or simply misunderstood.

Levinia leaves us all a major, important and extensive legacy to carry forward, with countless lives impacted by her energetic, pragmatic, visionary, brave and can-do approach.

It is incumbent on us to take the sadness and the loss we feel, and ensure that we continue to voice what must be heard; a voice that builds upon Levinia's work and passion over the years.

Levinia believed we all played a part and she believed that together we are the sum of us.

With love from your community

OCTOBER 2017

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Following the path of a leader in public health

Levinia Crooks, AM

28.11.1960 – 16.10.2017



Levinia Crooks, AM, Chief Executive Officer of the Australasian Society for HIV, Viral Hepatitis and Sexual Health Medicine (ASHM) and Adjunct Associate Professor, The University of New South Wales and Latrobe University died on October 16th 2017 from progressive non-Hodgkin Lymphoma.

She was awarded a Member of the Order of Australia (AM) in 2008 for her services to HIV and the President's Award from the AIDS Council of New South Wales in 2015 for her leadership in the HIV sector.

Levinia graduated from University of Wollongong with a Bachelor of Arts degree with Honours in Psychology and a Masters of Business Administration from the University of New England.

In the 1980s, at the very beginning of the AIDS epidemic in Australia, she became the manager for the Wollongong AIDS Research Project. Levinia went on to become the first executive officer of the National Association of People with HIV Australia (NAPWA), helping to found the networks that became the basis of Australia's world-leading collaborative government and community sector public health response.

Her work throughout the 1990s included running counselling workshops for the Northern Territory AIDS Council, formulating an evaluation strategy for services to people living with HIV and AIDS with the Commonwealth government, and developing a national media campaign promoting health monitoring and early diagnosis for people living with HIV for the Australian Federation of AIDS Organisations. She managed the HIV Prescribers Continuing Medical Education Project for the South-Eastern Sydney Area Health Service in the late 1990s.

From late 1999, she was the Chief Executive Officer of ASHM, a position she held until ill-health forced her retirement in September this year.

Under her leadership, ASHM extended its mandate from HIV to viral hepatitis and sexual health. She brought with this change, the values and principles that shaped the HIV response from the beginning – outstanding advocacy, meaningful partnerships, a priority on community-based and patient-centred care and engagement at all times of people living with HIV, viral hepatitis or sexually transmitted infections (STIs).

Amongst her many contributions during her tenure at ASHM, she advocated for, contributed to and shaped the national strategies for HIV, viral hepatitis and STIs and more recently a separate strategy for Blood Borne Viruses and STIs in Indigenous people. She co-ordinated the application to the Pharmaceutical Benefits Advisory Committee to remove the limitations on prescribing antiretrovirals based on CD4 count, making Australia one of the first countries to approve the initiation of antiretroviral treatment for all people living with HIV. She advocated tirelessly for appropriate pricing of direct-acting antivirals for hepatitis C and led the development and implementation of national guidelines for the use of pre-exposure prophylaxis for the prevention of HIV infection.

Within the Asia Pacific region, ASHM has become widely known for its outstanding education programs, successful advocacy with government and its commitment to developing multidisciplinary leadership across the sector. Many similar organisations across the region model themselves on ASHM and representatives often sought Levinia's advice and mentorship. Her commitment to bringing services to those living with HIV, viral hepatitis or STIs was as well-known in Port Moresby as it was in Sydney and Melbourne.

I had the pleasure of working closely with Levinia as CEO of ASHM when I was President of ASHM from 2005-2007. We also worked closely together

as members of the organising committees for the 7th International AIDS Society meeting on HIV Pathogenesis in Sydney in 2007 and the 20th International AIDS Conference in Melbourne in 2014. Both meetings were major international events that brought thousands of people from the HIV sector across the globe to Australia

I saw Levinia's capacity for hard work, her outstanding skill in bringing diverse groups together and her ability to form professional relationships with everyone and anyone. She did her work with passion and an unwavering commitment to science, evidence based practise, robust and informed government policy and a deep understanding that engagement of community was at the centre of everything. She loved Australia and was immensely proud of all that the sector had achieved in Australia's response to HIV and wanted the same approach to be shared and adopted by our neighbouring countries.

Throughout Levinia's tenure as CEO of ASHM, she worked with almost every clinician, researcher and community leader in the HIV, viral hepatitis and sexual health sectors. Particularly in the HIV sector, she has influenced, mentored and inspired an entire generation of professionals. She taught us all a way of making a difference in the work each of us do – to be strategic, be inclusive, do it in partnership, always use the best evidence to inform practice and never be complacent. Levinia was the consummate professional – but she always brought to her work warmth, empathy and a sense of fun.

Acknowledgements of Levinia's death are littered with words of strength and respect. She befriended, encouraged, persuaded, inspired, challenged, was tireless and passionate, extraordinary, energetic and influential. For those who worked with her, her passing is intensely sad. For those who follow in her path, it is worth considering the incredible impact one person can have.

Professor Sharon Lewin

DIRECTOR, THE PETER DOHERTY INSTITUTE FOR INFECTION AND IMMUNITY

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