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# **Transnational networks of influence in South African AIDS treatment activism**

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## Abstract

*It is often asserted that civil society participation contributes to successful HIV/AIDS policy formulation and implementation. However, the relationship between civil society advocacy or activism and the broader societal response is complex, under-theorised and probably varies significantly between countries. Any analysis of AIDS activism must therefore employ deeply contextual and rich empirical description.*

*One of the world's most prominent AIDS activist movements, the Treatment Action Campaign (TAC), emerged in South Africa, where the scale of the epidemic and the government's resistance to evidence-based responses (such as antiretroviral treatment) resulted in the disease becoming highly politicised. The TAC is widely credited with the dramatic policy turnaround in South Africa. This study draws on a range of conceptual and theoretical frameworks — among them the sociology of social movements, the political philosophy of civil society and the study of 'transnational advocacy networks' to investigate the TAC's operation and the source of its apparent success. It proposes a conception of transnational networks as 'networks of influence', including (but not limited to) the actors normally referred to in transnational advocacy networks. The study relies on extensive interviews with key TAC leaders, and offers a detailed account of the TAC's building and leveraging of networks of influence to affect HIV/AIDS policy.*

*These informal but robust networks have been built and maintained largely by a small group of key individuals within the organisation, and are often (but not always) built on strong ties of trust (sometimes predating participation in the TAC). Network participants include AIDS activists (particularly in the US), local and international scientists, individuals within allied civil society organisations, members of South Africa's political elite and individuals within state institutions. It is concluded that these networks of influence are key to explaining the TAC's success.*

# 1. Introduction

Judging by its prominence, it is hard to believe that the Treatment Action Campaign was founded by a mere fifteen people in 1998. It is now widely considered the most important AIDS activist organisation in the world and certainly the most successful of South Africa's post-apartheid social movements (Friedman and Mottiar, 2006:24).

Given the South African President's public questioning of conventional AIDS science and his government's resistance to using antiretrovirals both for prevention and treatment — widely seen as the product of 'AIDS denialism' at the highest level<sup>1</sup> — it is perhaps not surprising that South African AIDS policy would become hotly contested terrain. The scale of the human tragedy raised the temperature of public debate to a level not reached by 'everyday' political issues and the moral imperative of an issue that is literally one of life and death emboldened social actors who may not otherwise have taken a stand. When the TAC launched a civil disobedience campaign against government intransigence in 2003 — no small step, given the symbolic significance of resorting to breaking the law in a newly-democratic South Africa — it had the support of a wide cross-section of South African society, including most of the media, civil society organisations (though not explicitly that of the Congress of South African Trade Unions, arguably the TAC's most important ally) and large sections of the public.

But what certainly is remarkable, is the success that a relatively small and newly-formed movement could achieve against strongly vested interests

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<sup>1</sup> South Africa's President Thabo Mbeki started publicly questioning the viral aetiology of AIDS, as well as the safety and efficacy of proven treatments (especially AZT, calling it "toxic") shortly after assuming the Presidency in 1999. He had been in contact with a number of notorious AIDS denialists and later established a Presidential AIDS Advisory Panel, inviting roughly equal numbers of scientists and denialists ("dissident scientists"). The Minister of Health, Manto Tshabalala-Msimang became his staunch ally in his subsequent battles with activists and the scientific establishment. Against the advice of South African and international clinicians and public health experts, the Mbeki government refused to implement a mother-to-child transmission prevention programme until compelled to do so by the country's highest court (in a case brought by the Treatment Action Campaign). An antiretroviral treatment programme was not implemented until 2003, after a protracted struggle by activists. For a detailed account of AIDS denialism and its consequences in South Africa, see Natrass (2007).

and powerful adversaries, notably the state and large pharmaceutical companies. The most significant successes include the withdrawal of multinational pharmaceutical firms from a legal challenge to legislation which threatened their ability to profit from patented medicines,<sup>2</sup> a very substantial reduction in the average price of antiretroviral drugs and other key drugs used in the treatment of AIDS and associated diseases (the result of a broad range of actions), the litigation which resulted in the Constitutional Court ordering the government to implement PMTCT<sup>3</sup> and the South African government's September 2003 decision to reverse its policy and implement a national ART programme. In analysing the emergence and remarkable success of the TAC — other social movements have been markedly less successful in post-apartheid South Africa — both contextual factors (such as changes in political and legal institutions and ruling-party politics) and the specific characteristics of the TAC must be taken into account. The latter includes its organisational structure, its tactics and what I will term its 'struggle heritage,' i.e. its embeddedness in and deliberate employment of the tradition of anti-apartheid struggle in South Africa. The TAC is often held up as a model for activism and civil society leadership on AIDS as well as for other social movements. It is therefore necessary to interrogate carefully how its apparent successes came about — keeping an open mind as to whether these are the result of deliberate and replicable strategies or the contingencies of the South African context.

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<sup>2</sup> The Medicines and Related Substances Amendment Act, passed in 1997, aimed at allowing the government to reduce the cost of patented medicines by allowing for 'parallel importation' (import of the originator company's product by another party) and, depending on interpretation, compulsory licensing of pharmaceutical patents. Almost immediately the Pharmaceutical Manufacturers' Association of South Africa challenged the Act, filing notice of motion in 1998 challenging the constitutionality of the Act, as well as its compliance with the Trade Related Intellectual Property Rights Agreement (TRIPS), of which South Africa is a signatory. Only in 2001 did the case come to Court, but after less than a month and a vigorous campaign by the TAC and its allies (both within South Africa and internationally), the parties settled out of Court (see Cleary and Ross, 2002). Commentators have variously ascribed this to the activist pressure (e.g. Friedman and Mottiar, 2005:511) and to the public relations disaster the case turned into for the companies (e.g. Van Niekerk, 2005:58).

<sup>3</sup> Prevention of Mother-to-Child Transmission of HIV. This is done by administering a short course of one or more antiretroviral drugs to the mother prior to delivery and to the newborn after birth. The simplest (though not most effective) PMTCT regimen involves a single dose of Nevirapine to the mother before and to the baby after delivery and reduces the rate of transmission by about half. Other regimens are more complex but even more effective.

This preliminary case study forms part of a larger research project investigating ‘AIDS leadership’ — increasingly recognised as crucial in the continuing battle against the HIV/AIDS epidemic. While the inherently normative question of (good) leadership is a difficult to pin down, this broader project is informed by the postulate that the emergence of ‘coalitions’<sup>4</sup> for AIDS treatment is a critical precondition for successful AIDS responses (and ART programmes in particular). These coalitions generally consist of diverse actors, including states, multilateral institutions (principally institutions in the UN family, like the World Health Organisation and the Joint United Nations Programme on HIV/AIDS), civil society (both at the national and transnational levels) and even the private sector. It is important to note that the existence of an AIDS treatment coalition does not imply an end to contestation; rather, coalitions often involve ‘sufficient consensus’ on certain core questions and the continual management of conflict, such that the political context remains conducive to an effective AIDS response. The emergence or not of such coalitions and the actors and processes giving rise thereto show wide variation. However, in a number of significant examples, including Brazil, Thailand and South Africa, AIDS activists arguably played the critical role in driving a governmental and societal response, among other things by placing ART on the political agenda (even if the form of activist engagement is highly context-specific). Even in the global treatment access movement (which can itself be seen as an AIDS treatment coalition) activism was arguably the driving force. The national and international levels can of course not be divorced from one another, since national and transnational actors and institutions influence one another and are often richly interconnected. This suggests that complex international patterns of interaction and influence are key to explaining the influence of activists.

The South African case study therefore seeks to illuminate the processes by which South African AIDS activists gained influence, managed to frame the question of ART politically and contributed to the emergence of an AIDS treatment coalition (albeit a fraught one which continued to be obstructed by certain key actors). It is divided into two parts, the first of which is included in this paper. The first part focuses on the mobilisation of influence, both through narrow activist networks and broader networks of influence in which a diverse set of actors participate, including local and international activists,

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<sup>4</sup> For a discussion of how the notion of ‘coalitions’ is useful in understanding what good leadership entails in the context of development policy, see Leftwich and Hogg (2008).

AIDS scientists and clinicians, individuals within allied civil society organisations, members of the South African political elite as well as individuals within state institutions. The second part (to be published separately), provides an account of the political and moral framing of the AIDS treatment issue and the emergence of an AIDS treatment coalition built on the foundation provided by the solidarity networks and networks of influence.

## 2. A network approach to AIDS activism: 'networks of influence'

An earlier paper that forms part of this research project and entitled "Networks of influence: A theoretical review and proposed approach to AIDS treatment activism" investigates the theoretical questions confronting research into AIDS activism in detail. It reviews a set of promising theoretical approaches, and proposes an approach that seeks to explain the impact of AIDS activism in terms of 'transnational networks of influence.'

The theoretical approaches reviewed can be broadly categorised as (1) the sociology of political contention, particularly the study of 'social movements'; (2) a network model of political organisation and contestation; and, to a lesser extent, (3) the political philosophy of civil society. The latter is useful in particular because it serves to inform a politically and ethically engaged account.

Social movement theory focuses on the structural preconditions and means for collective political action, and considers three broad sets of factors: (1) the structure of political opportunities and constraints facing the movement; (2) the forms of organisation (both formal and informal) available to participants (also called 'mobilising structures'); and (3) the collective processes of interpretation, attribution, and social construction that mediate between opportunity and action, known as 'framing processes' (McAdam et al., 1996:2).

A basic assumption of social movement theory is that the emergence, form and success or failure of social movements can be explained largely in terms of structural factors, such as political opportunities and constraints imposed by elements of the environment (e.g. the relative openness or

closure of the institutional political system). I have argued that this assumption reflects the state-centric and domestic bias of the approach, which limits its usefulness in the analysis of transnational social movements — or movements that rely on transnational processes for a substantial part of their influence (Grebe, 2008).

In the theoretical review (Grebe, 2008); I trace the rise of network and systems thinking in the social sciences, most prominently reflected in ‘social network analysis.’ These approaches consider individuals primarily as nodes in networks (rather than as repositories of individual agency), and focus rather on the webs of interrelationships between individuals. This allows it to account for ‘network effects’ that result cumulatively from these relationships rather than the characteristics of the nodes themselves. While not an exercise in formal network analysis, the focus in this paper on networks reflects the conviction that the notion of network effects are useful in explaining how relatively small groups of activists have often been able to ‘jump scale’ — i.e. to exert influence far greater than their number or apparent social power would suggest. Nevertheless, I do insist upon individual agency as an important factor, though the role of individuals can often be explained in terms of their strategic position in networks (for example, the ability to connect two divergent social groups or spheres of action).

The study of ‘transnational social movements’ is an approach that draws on the network perspective and that is far better able to take account of the transnational dimension of AIDS activism. The international environmental and human rights movements are most often cited as examples. According to Keck and Sikkink (1998:1), transnational advocacy networks “multiply channels of access” to the international system by creating new links among actors in civil societies, states, and international organisations. In this way, civil society actors are able to exercise greater influence over policy. They define networks as “forms of organisation characterised by voluntary, reciprocal, and horizontal patterns of communication and exchange” (Keck and Sikkink, 1998:8). Their main argument is that the impact of activism at the domestic level is to a significant extent a function of these transnational networks.

Four tactics are typical of these networks: (1) *information politics* (quick generation of credible politically useful information and moving it to where it

will have the greatest impact); (2) *symbolic politics* (employing actions and stories that make sense of a situation to an audience that is often far away); (3) *leverage politics* (calling upon powerful actors to affect a situation that less powerful network members are unable to influence); and (4) *accountability politics* (holding powerful actors to their previously stated positions or policies) (Keck and Sikkink, 1998:16–25).

This conception of transnational advocacy networks is powerful, and appropriately refers to the links between actors within various spheres of the international system. However, in my view the network model should be expanded to include not only networks of activists and NGOs, but also other actors, so that we are describing webs of influence that may include scientific communities, international bureaucrats, diplomats, but even extending to individuals and institutions within the target state (see also Grebe, 2008). In what follows it will become clear that much of TAC’s influence has derived from the transnational networks of influence that it was able to construct and/or leverage.

### 3. Origins of the Treatment Action Campaign

The TAC was founded on International Human Rights Day (10 December) in 1998 by Zackie Achmat and a handful of friends and old comrades — mostly people who had been active together in the anti-apartheid struggle in Cape Town in the 1980s. The group stood on the steps of St George’s Cathedral in Cape Town, handing out pamphlets to passers-by calling for greater access to antiretroviral treatment. Many of these people told the group that they had never known AIDS could be treated: “Passers-by were surprised. Not many of them knew that you could treat AIDS. They didn’t realise that AIDS medications were freely available in Western Countries” (TAC, 2001:2).

Shortly before, at anti-apartheid and gay rights activist Simon Nkoli’s memorial service in November 1998, Achmat had called for the creation of a campaign for access to antiretroviral treatment. In his speech, he acknowledged that “government cannot do everything” but appealed to the government to work with the new campaign to bring down the cost of

treatment so that it can be made more widely available.<sup>5</sup> As reflected in this statement, it was expected that the campaign would face strong opposition from the pharmaceutical industry, the pricing policies of which presented the most salient obstacle to the wider availability of antiretroviral drugs.<sup>6</sup> As it turned out, a larger obstacle became government intransigence.

It is significant that the initial announcement was made at the funeral of Nkoli — who had died of AIDS, unable to access appropriate treatment. He was considered especially courageous for having decided to come out as gay to his ANC comrades at the time that he stood trial for his anti-apartheid activities.<sup>7</sup> Achmat knew and worked with Nkoli in early 1990s gay rights activism.<sup>8</sup> Nkoli's death shook his friends and comrades and brought home to many the stark reality of the high cost and difficulty of obtaining correctly administered treatment.<sup>9</sup> In describing its own origins, the TAC has referred to Simon Nkoli's death of AIDS in November 1998 as a defining moment (TAC, 2001:2).

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<sup>5</sup> Part of the speech can be seen in the video documentary "TAC: The first five years..." (Lewis, 2003).

<sup>6</sup> Personal communication with Zackie Achmat.

<sup>7</sup> In November 1986, close to 20 activists from the Vaal triangle, Nkoli among them, were charged with treason together with a number of senior United Democratic Front leaders, including present Minister of Defence Mosioua Lekota in the so-called Delmas treason trial (Seekings, 2000:145). He later became the leader of the Gay and Lesbian Organisation of the Witwatersrand (GLO).

<sup>8</sup> It should be noted that Achmat was not personally close to Nkoli: ". . . of course, Simon was never a friend of mine, but I had enormous respect for him as a leader who put, who was enormously courageous, he was personally probably one of the most courageous people I have known . . . but irrespective of whether you regard him as a friend or not, he was a leader and someone I recognise as my leader because I didn't have the same courage. I didn't have the same courage as he did politically with being gay. . . . Irrespective of his leadership failures in GLO and elsewhere, his contributions to HIV, his contributions to gay and lesbian equality, his contributions to the anti-apartheid struggle, those were more than enough to give him a place in all our hearts and in our history." (Interview, Achmat, 30/04/2008)

<sup>9</sup> Achmat says of his death, ". . . Simon having intermittent treatment and having tried Virodene and so on and [having] kidney failure and died as a consequence of not having proper medical treatment, not having medical treatment through a public healthcare programme" and cites the contrast between Nkoli's experience and that of Edwin Cameron (who recovered rapidly from AIDS after going on ART in 1996) as crucial in his forming an understanding of what ART could do (Interview, Achmat, 30/04/2008).

The TAC's relatively inauspicious beginnings nevertheless point to some of the most important characteristics that I will elaborate in this paper. These include:

the critical role played by deeply committed activists schooled in the political lexicon of the Struggle (against apartheid);

the rootedness of the campaign, its self-conception, goals and strategy (i.e. 'framing practices' and 'repertoire of contention') in the history of struggle familiar to its founders (including 'entryist' and Trotskyist revolutionary activity, struggles for gay and lesbian equality and the linked history of AIDS activism in the US);

the reliance on personal relationships and strong ties of friendship, affection and trust (that to a significant degree predate the formation of TAC) to mobilise a core of activists (even after the organisation became more formal and democratic);

the centrality of moral appeals (the message was always that treatment should be available because that is what justice demanded, not because the activists demanded it);

the use of strongly symbolic gestures (St George's Cathedral is the church where Archbishop Desmond Tutu was based and was a favoured venue for public meetings organised by the United Democratic Front; the choice of a UDF symbol is indicative also of the desire to build as broad as possible a coalition around AIDS treatment (see page 23));

the centrality of a human rights-based approach, as illustrated by the choice of Human Rights Day;<sup>10</sup> and

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<sup>10</sup> Human Rights Day is celebrated on 10 December each year in commemoration of the day in 1948 on which the United Nations General Assembly adopted the Universal Declaration of Human Rights. While there will be frequent references to the human rights approach evident in the TAC's work — evidenced among other things in the very frequent references to constitutional rights in its leaders' statements and in campaign materials, as well as in the litigation under the South African Bill of Rights which has constituted a key part of its work — this question (for reasons of space) does not receive the attention it deserves in the present paper. See also Johnson (2006).

the importance of public education on the science of HIV and HIV treatment for its campaign.

But these events do not yet clearly reflect what I will argue is one of the most important sources of the TAC's impact: its construction and leveraging of (transnational) networks of influence — including the effective mobilisation of international solidarity and influence through the building of activist and support networks; as well as the informal but robust networks of influence (both inherited from individuals and meticulously built over time) which connect individuals (including many who would not or could not openly support the organisation) from diverse fields such as science, international organisations, foreign governments, state institutions and political parties, including the African National Congress.

These characteristics will be explored further in the sections that follow.

#### 4. From the struggle against apartheid to activism under democracy

The Treatment Action Campaign's decade of existence cannot be understood without looking at the continuities between it and its historical precursors, in particular the anti-apartheid struggle (and the variety of Trotskyist agitation in which many of its founders engaged), gay activism and American AIDS activism. However, it is by no means a passive recipient of political history: while consciously drawing upon its history, it also continuously (and strategically) refashions that political legacy.

Many (though by no means all) of the TAC's leaders are veterans of the anti-apartheid struggle. Several authors, as well as the TAC's leaders themselves,<sup>11</sup> have pointed to what one could term the TAC's 'struggle heritage' as central to its self-conception as well as to its engagement within the South African polity. The continuities with this history manifest in a number of ways, including in its political style and strategy and its use of symbolism and culture — what Robbins (2004) has called the "creative reappropriation of locally embedded political symbols, songs and styles of

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<sup>11</sup> E.g. Interviews, Achmat 16/06/2007 and Heywood, 17/12/2007 & 10/01/2008.

the anti-apartheid struggle.”<sup>12</sup> Its situation within this tradition also provides it with legitimacy that opposition politics in South Africa generally does not enjoy. Friedman and Mottiar (2006:25), for example, point to the similarity between the tactics employed in the struggle against apartheid and those employed by the TAC. These include the use of the courts, international solidarity, broad alliances and (occasionally) civil disobedience. Its focus on mass mobilisation is arguably related to the involvement of key leaders in the campaigns of the United Democratic Front during the 1980s.

The TAC has framed its struggle with a ‘human rights discourse’, arguing that access to life-saving treatment is a fundamental human right (see Mbali, 2006; Johnson, 2006). That this is the primary framing of TAC’s demands becomes apparent with even a cursory review of its pamphlets, posters, documents and public statements. This rights-based discourse also represents the intersection of what I call the ‘politics of moral consensus’<sup>13</sup> and a key TAC strategy, namely the use of litigation to enforce the legal rights conferred by the new South African Constitution. By frequently stating that the rights it insists upon are guaranteed by the Constitution, it both strengthens the moral force of its appeal by locating it within the trajectory of South Africa’s liberation and makes clear that its challenge is not to the legitimacy of the government or the state, but to government policies. This is critical for the legitimacy of its own discourse in the political context within which it operates — Zackie Achmat himself has acknowledged that the TAC risked losing the support of its own members if it were “seen to be threatening democratically elected leaders” (quoted in Friedman and Mottiar, 2006:25). But this goes beyond the avoidance of risk and, as Friedman and Mottiar point out, the TAC strategically exploits its struggle heritage:

TAC’s location, albeit in ambiguous fashion, in the ANC tradition also gives it an important asset: it enables it to use the imagery of the ANC’s anti-

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<sup>12</sup> The TAC employs the political lexicon of the struggle. Like political rallies of the ANC, UDF and the other liberation movements during apartheid, speakers at TAC events commonly start with the right-fisted salute and the cry “Amandla!” (power), which the audience answers with “Awethu!” (to the people). Members address each other as “comrade”, sing struggle songs (the words of which have been altered to refer to the TAC’s demands) and toyi-toyi at protest marches.

<sup>13</sup> This formulation is derived from Achmat’s own frequent statement that TAC owes much of its impact to its success in constructing a moral consensus around access to treatment (e.g. Interview, Achmat, 16/06/2007).

apartheid struggle as an important “discursive tool” in its attempt to achieve legitimacy and moral support. It has referred, for example, to its civil disobedience campaign as a “Defiance Campaign,” evoking a celebrated ANC campaign against apartheid laws in 1952. (Friedman and Mottiar, 2005:522)

That location is certainly ambiguous. Zackie Achmat, Mark Heywood, Jack Lewis, Deena Bosch, Laddie Bosch, Sharon Ekambaram and Herman Reuter are early TAC activists who were members of the ‘Marxist Workers’ Tendency of the ANC’ (MWT) — a Trotskyist group active in exile and underground in South Africa during the 1980s. According to Heywood, those early TAC cadres drew on their shared experience, and specifically a common “method of analysis and work” developed in the course of their revolutionary activity.<sup>14</sup> This included a common analysis of the state and state power, derived to a significant extent from Marxist thinking<sup>15</sup> and a shared emphasis on the importance of mass mobilisation.

Arguably, the TAC’s loyalty to the ANC as liberation movement while at the same time not shying away from holding the party and the ANC government to account (including a willingness to engage in open conflict) also derives from the early cadres’ experiences in the MWT. Lewis recalls the view that revolutionary activity had to be undertaken under the ANC umbrella, but also an awareness of the “problematic” ANC leadership. Despite its name, the MWT was not tolerated by the ANC. While Achmat himself was never formally expelled from the ANC, almost the entire MWT leadership (including Rob Petersen, Martin Legassick and Paula Ensor) were.

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<sup>14</sup> Interview, Heywood, 10/01/2008. Notably, both Heywood and Achmat pay tribute to Rob Petersen (now an advocate practising in Cape Town but in exile in London at the time) as a political mentor to whom they owe much of their strategic thinking. Achmat remains friends with Petersen and often consults him informally on questions of tactics.

<sup>15</sup> It should be noted that most of these former MWT members no longer pursue revolutionary socialist politics. Says Heywood (interview, 17/12/2007): “I stopped basing my politics directly on Marxism, although to this day I’d still point to the value of a lot of Marxism, a lot of Marx’s analysis, a lot of Trotsky’s analysis and so on, and I’d still, to this day, describe myself as anti the excesses of capitalism and I’d still argue that capitalism is fundamentally unequal.” Heywood amusingly recounts Achmat adopting various political labels — including ‘radical democrat’ — in the early 1990s after leaving the MWT (interview, 17/12/2007), and Achmat now calls himself a ‘social democrat’ (personal communication). Others like Lewis eschew political labels while retaining significant elements of Marxist analysis.

Interestingly, the TAC was not the first health-focused initiative by former MWT members. The Bellville Community Health Project (part of the Progressive Primary Healthcare Network), run by Achmat, Lewis and Deena Bosch in the early 1990s, provided experience with and knowledge of health policy questions and, more importantly, experience with health-focused community mobilisation.<sup>16</sup> Even the focus on drug prices and the use of generics to bring them down derives to an extent from the experience.<sup>17</sup>

Mbali (2006) attempts to show how earlier traditions of both gay rights activism and anti-apartheid activism shaped the TAC. This is an important corrective to the usual tendency of concentrating only on the struggle heritage; and taken together with the heritage of global AIDS activism in the American AIDS activist movement which built on the gay rights struggles of the 1970s, calls into question the radical separation of identity-based ‘new social movements’ and the ‘new new social movements’ of which contemporary AIDS activism is arguably an important example. Nevertheless, the TAC’s struggle is clearly not rooted in identity politics, and a nuanced historical perspective must acknowledge both continuities and discontinuities with identity-based struggles.

Mbali (2006:134) argues that “the emergence of anti-apartheid, gay rights activism situated in universal rights-based discourse provided the basis for such gay rights activists to form broad-based, human rights-focused alliances, such as TAC, in the post-apartheid era.” Certainly it is true that some of the strategies that the TAC has employed with great success — such as constitutional litigation — can be traced to key activists like Achmat’s role in prior gay rights activism. After Nkoli’s death Achmat led the NCGLE at the time that it launched two landmark cases in the early post-apartheid period, successfully challenging the continued criminalisation of sodomy and the unequal treatment of foreign spouses and same-sex partners of South Africans in terms of the Bill of Rights in the new South African Constitution.<sup>18</sup>

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<sup>16</sup> Interviews, Achmat, 16/06/2007, Lewis 24/11/2007 and Bosch, 26/11/2007.

<sup>17</sup> Interview, Achmat, 30/04/2008.

<sup>18</sup> National Coalition for Gay and Lesbian Equality and Another v Minister of Justice and Others 1998 (12) BCLR 1517 (CC); and National Coalition for Gay and Lesbian Equality and Others v Minister of Home Affairs and Others 2000 (1) BCLR 39 (CC).

The anti-apartheid struggle, gay rights activism and the new struggle for access to AIDS treatment were linked in the minds of the early TAC activists, and they relied both on the skills they had acquired and the relationships that had been established during the earlier struggles in embarking on the new.

## 5. Mobilising through networks

I have already alluded to the critical role of networks — both formal and informal — in AIDS activism, and of the individuals who engage in the relationships that make up the links in these networks. These relationships take many forms and range from personal ties of affection and loyalty to impersonal and formal working relationships and even to ad hoc, strategic cooperation. In this section I explore how the personal political networks of the TAC's founders helped in establishing the new campaign, how the organisation grew beyond this initial circle, and how local and international support networks (comprising, inter alia, other activists, civil society organisations and clinical and scientific communities) were built to augment local community mobilisation. Though this will be the subject of a separate paper, I also present a preliminary analysis of how these networks were leveraged to build an AIDS treatment coalition.

### **Personal networks: a resource for movement building**

The interlinked networks of activists that early TAC leaders had built up prior to TAC's founding, including anti-apartheid, social justice and gay rights activists and in particular the network of former Marxist Workers' Tendency members became an important resource in the building of the TAC, particularly with respect to (1) a shared political outlook, (2) a network of people that could be drawn on to mobilise resources for the new campaign and (3) relationships of trust which could underpin the new TAC's leadership. Heywood explains it as follows:

I think the [MWT] experience was important, and I think part of the experience was that a group of us had already established a way of working together and a certain level of trust. And I think there was a kind of unconscious method that had been developed, a political method, a way of thinking about the government, about the state, about social organisations,

about social mobilisation and so on. You know the Tendency people provided the initial cadre that was needed to get TAC up and running. Let me just say that it was never a deliberate plan, it wasn't as if we reconstructed the Tendency grouping for TAC. It was just the group of people whom Zackie, in particular, drew on when we started up TAC... that group of people and their connections, people like myself, Sharon [Ekambaram] came in early, Laddie Bosch, Deena Bosch, and other people. . .<sup>19</sup>

Achmat argues that the “institutional memory of activism” is a resource that the organisation actively taps:

... You require... a body of educated activists, and by that I don't mean a middle-class body. It means a body with a knowledge that is institutionally transmitted.<sup>20</sup>

While he underplays the importance of individuals (“not through any individual, but through our collective knowledge”<sup>21</sup>) in making available this knowledge to the organisation, he nevertheless acknowledges the importance of certain key individuals.<sup>22</sup>

In addition to the skills and experience they bring, individuals can make available to the movement their established networks. The social networks of individuals are both a means by which the movement is initially launched (until it is established enough and has gained enough momentum to start drawing people in) and a strategic resource available to the movement.

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<sup>19</sup> Interview, Heywood, 10/01/2008.

<sup>20</sup> Interview, Achmat, 16/06/2007.

<sup>21</sup> Interview, Achmat, 16/06/2007.

<sup>22</sup> Says Achmat:

... I think that we have have a very powerful team of leaders and there is complexity in that team and as it's operated over the years. You will have someone like me, who is probably a very domineering and dominating personality, who makes, who has a long experience, at the time of the start of TAC about 25 years experience in politics... and you'd have Mark Heywood with also about 20 years of experience, you'd have Theo Steele [senior trade unionist and early TAC activist] with 30 years of experience in politics, you'd have someone like Herman Reuter with 20 years in politics, you'd have someone like Siphon Mthathi with about 5 years in student activism... and then a serious history in TAC. So you'd have any number of people from Nonkosi Khumalo, later Vuyiseka Dubula, Nathan Geffen who did not have any political experience, but brought enormous scientific experience and technical capacity to TAC. (Interview, Achmat, 16/05/2008)

As is clear from the history of TAC's origins briefly recounted earlier, and from what the activists themselves say, trust is a critical element of the networks used to build up a movement.<sup>23</sup> Certainly the relationships of trust built up during MWT activities (particularly between Achmat and Heywood) were a key resource in building the new movement. While both underplay this dimension, it is clear from what they do say that there is an unusual rapport between the two<sup>24</sup> and a meeting of minds that has resulted in their becoming the strategic and tactical 'masterminds' of the TAC.

The leadership of the organisation (including senior staff members and elected officials) exhibit an exceptional degree of deference to Achmat and Heywood on matters of political strategy.<sup>25</sup> Significant and strategic decisions such as the initiation of legal action or civil disobedience has often resulted from ideas raised by either Achmat or Heywood with consensus rapidly emerging in the National Executive Committee (NEC)<sup>26</sup> — the highest policy-making body of the TAC between National Conferences — and the Secretariat (elected officials who make day-to-day decisions). TAC leaders acknowledge the existence of an informal 'core group' of leaders

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<sup>23</sup> The high level of trust often derives from the blurring of personal and professional relationships. It is impossible to spend time with the TAC leadership without forming the impression that there exists genuine friendship between most of the individuals involved. Lewis and Achmat are former lovers and still share a house, while Heywood, Deena Bosch, Reuter and Jonathan Berger (senior AIDS Law Project researcher) are close friends of Achmat. Nathan Geffen (a TAC leader who came to play a central role in the organisation's activities), Siphon Mthathi, Vuyiseka Dubula and Mandla Majola later became equally good friends with Achmat. Heywood and Sharon Ekambaram married while working together in the MWT in the early 1990s, and even a number of the later generation of leaders have close personal ties (Majola and Dubula became partners, for example). Other friendships reaching outside the immediate TAC circle, such as that between Achmat and Edwin Cameron — a judge and former director of the Centre for Applied Legal Studies (CALS) — are also notable for their role in building networks of influence.

<sup>24</sup> Says Sharon Ekambaram (Heywood's wife and MWT and TAC activist), "Mark and Zackie have an incredible connection, and it just cannot be explained, and I don't think that's, I think it's one of the strengths of TAC in that while they have disagreements, they can have disagreements but they discuss almost everything, you know it's just... they... I don't know if it's the same now, but for a while they couldn't go without a day, talking three or four times, but work-related..." (Interview, Ekambaram, 11/01/2008)

<sup>25</sup> The author has directly observed this, and it is confirmed by several interviews (Berger, 16/12/2007; Bosch, 26/11/2007; Dubula, 18/04/2008; Ekambaram, 11/01/2008; Geffen 19/04/2008).

<sup>26</sup> The NEC was restructured and renamed the National Council at the March 2008 National Conference.

around Achmat and Heywood that during the early years of the TAC's existence effectively made the important decisions. Later, this group generated most of the strategic thinking that informed important decisions of the formal structures.<sup>27</sup> Both the trust that underpinned decision-making, and the fact that this did not necessarily imply unanimity is illustrated by the example of the decision, in 2000, to import generic fluconazole from Thailand in defiance of Pfizer's patent in South Africa. Planning for this action (dubbed the Christopher Moraka Defiance Campaign) proceeded largely without Heywood's involvement, and upon learning of it, he was initially unconvinced — fearing that it would not be understood by TAC's membership or the general public.<sup>28</sup> He acknowledges that Achmat had to "push that through," but cites it as an example of where Achmat's leadership proved vital to TAC's success.<sup>29</sup>

However, as the organisation grew, structures became more formal, members organised in branches became more influential, new leaders rose through the ranks and a significant staff complement managed an increasing number of formal programmes with large budgets. Achmat and Geffen point out that significant proposals put forward by Achmat and Heywood have been overturned by opposition from the rank and file or in

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<sup>27</sup> Says Nathan Geffen:

[Decisions were made in the early years] quite differently from the way they're done now. . . . First of all the decision structures and the organisation at the time were very informal, it was a small organisation and a group of us, by way of informal communication, made decisions, carried out decisions. There were very few staff members, two or three, and the staff members were actually quite low down [laughs] in the scheme of things at that time. . . There was an interim executive, if I remember correctly, but there wasn't a properly established formal structure like there is now, and it worked quite well I have to tell you.

...

... there was an informal structure where decisions were made over the phone.

... I think any organisation must have [informal core groups of strategic thinkers]. I don't think that it's possible to operate on an entirely formalistic basis. I wouldn't know how one would actually do that, because before formal decisions are tabled there needs to be thinking around it... (Interview, Geffen, 19/04/2008)

<sup>28</sup> Interview, Geffen, 19/04/2008.

<sup>29</sup> Interview, Heywood, 17/12/2007. Says Heywood:

... at a number of critical moments in the history of TAC it was Zackie's intervention and direction — and it didn't require a fight to get other people to adopt it, but there were key turns that he caused TAC to make that may not have been made otherwise; and if they had not been made, then I don't think TAC would have created the, found the place that it has in the public imagination if you like.

the NEC. They independently cite the example of the proposal to accommodate a key ally, the Congress of South African Trade Unions (COSATU) during the 2003 civil disobedience campaign (by renaming the campaign a “mass protest campaign”), which was rejected by members and NEC members during deliberations.<sup>30</sup>

Despite the fact that the TAC leadership (in its membership and its functioning) has drawn heavily on pre-existing networks, it has become increasingly diversified, and what Achmat refers to as second and third generation leaders have become part of the web of trust-based relationships by which the TAC’s strategic decision-making is driven. Heywood acknowledges that the building of this second layer of leadership was a deliberate strategy of the earlier leaders, because “we realised that TAC needed a local and black leadership, particularly HIV-positive persons,”<sup>31</sup> and it was remarkably successful at pulling individuals like Mandla Majola and Vuyiseka Dubula and many others into both formal and informal decision-making processes. (Majola is an early TAC member recruited to its first branch in Gugulethu and who then helped organise its earliest branches in the townships of Cape Town; Majola later became National Organiser and a very prominent leader before returning to local activities as a ‘district organiser.’ Dubula is a young TAC leader who only joined the organisation in 2002 and later joined the Western Cape provincial staff. She was elected General Secretary — the most senior executive position in the organisation — at its 2008 National Conference.<sup>32</sup>)

This is not to suggest that the growth of TAC and the bureaucratisation of the organisation did not produce tensions and difficulties. At times there have been tensions at the regional level between paid staff members and volunteers/members or elected leaders serving on bodies like the Provincial Executive Committees (now Provincial Councils).<sup>33</sup> Tensions have also arisen over salary differentials between national and regional staff or

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<sup>30</sup> Interviews, Achmat, 16/05/2008; Geffen, 19/04/2008.

<sup>31</sup> Interview, Heywood, 10/01/2008.

<sup>32</sup> That early leaders were serious about building a new generation of TAC leaders is illustrated by the fact that both Achmat and Heywood relinquished their senior positions (as Chairperson and National Treasurer respectively) and did not make themselves available for reelection at the most recent Conference. Achmat stood unopposed for the position of Deputy General Secretary. Nonkosi Khumalo, a former TAC staff member who now works at the AIDS Law Project was elected Chairperson.

<sup>33</sup> Interviews, Dubula, 18/04/2008; Majola, 21/04/2008; Ramothwala, 11/01/2008.

perceived unnecessary interference in the work of regional staff members by national managers.<sup>34</sup> While tensions within both the senior leadership and the national management team arose periodically, these have in the main been managed successfully.<sup>35</sup> During 2007 a serious disagreement arose between the organisation's first elected General Secretary (Sipho Mthathi) and members of her management team on the one hand, and other elected officials including Achmat on the other. This led to a breakdown of trust that resulted in Mthathi and several other senior staff members leaving the organisation. In response to the crisis, an Organisational Review Commission was established, which recommended significant restructuring of the governance and management structures of the organisation, including a stronger oversight role for the National Council and Secretariat, aimed at preventing similar incidents (Achmat, 2008:15). These proposals were adopted by the organisation's National Conference in March 2008. Achmat has repeatedly blamed weak management systems for these problems,<sup>36</sup> and in his last report as Chairperson to the organisation's 2008 National Congress stated:

Historically, TAC leadership and management survived through trust and cohesion that was built through struggle and friendship. The dramatic growth of TAC and the new and complex political tasks, as well as, the day to day permanent crisis of implementation of HIV prevention and treatment required a different approach.

. . . A skilled political leadership in TAC has managed many of these issues over more than nine years. . . . To support skilled political leadership and a motivated membership, TAC requires a professional management and reliable systems that can function in the absence of individuals in leadership or staff. (Achmat, 2008:15–16)

However, the difficulties arguably result from a hybrid leadership model in which cohesion is maintained both through informal trust-based relationships and formal authority. Despite the difficulties, the TAC has managed to make a relatively successful transition from a small and highly flexible activist grouping held together by trust and a strong commitment to common goals, to a formal and bureaucratised organisation, which

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<sup>34</sup> Interviews, Dubula, 18/04/2008; Ramothwala, 11/01/2008.

<sup>35</sup> Interview, Geffen, 19/04/2008.

<sup>36</sup> Personal communication.

nevertheless retains many characteristics of the former. The hybrid model has served it well, but difficulties are likely to persist as it tries to incorporate the strengths of both ‘activist movement’ and ‘corporate NGO’ leadership models. Many other AIDS activist organisations, including ACT UP in the United States, failed to make similar transitions and as a result failed to sustain themselves (see Epstein, 1996; Smith and Siplon, 2006). Others, like Gay Men’s Health Crisis, remain strong, but do not have the political and radical character of true activist organisations.

### **Mobilising civil society alliances and international solidarity networks**

It is clear that personal networks and relationships constituted a key resource in building the movement. For example, Heywood’s position as director of the AIDS Law Project (ALP) — at that stage a project within the respected Centre for Applied Legal Studies at the University of the Witwatersrand — provided access to resources that the fledgling TAC would not have been able to mobilise on its own as well as the legitimacy of the association with Wits and CALS.<sup>37</sup> Heywood had in fact been hired to the ALP by Achmat, who became its director in the early 1990s, before leaving to become director of the National Coalition for Gay and Lesbian Equality (NCGLE). Important relationships were formed during this time, including through participation in consultative structures established by the Department of Health after the new government came to power in 1994, such as an NGO funding committee and other regular meetings between then-director of HIV/AIDS Quarraisha Abdool Karim and civil society representatives.<sup>38</sup> Later, after Abdool Karim had left government service, the relationship with her would remain important, and she made a crucial expert submission in the TAC’s litigation to compel the government to provide MTCTP. Some time after Achmat left the ALP, Heywood became its director.

When TAC was founded, the intention was not to ‘go it alone’, but to build a broad front of progressive organisations pushing for access to ART. It was envisaged that the TAC would be a campaign operating within the National Association of People Living with HIV/AIDS (NAPWA) and supported by a

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<sup>37</sup> The AIDS Law Project has since left the Centre for Applied Legal Studies and is now an independent NGO.

<sup>38</sup> Interview, Q. Abdool Karim, 09/06/2008.

range of organisations. The TAC later split from NAPWA, which Achmat attributes to entrenched interests which resisted its radicalisation and transformation into a mass-based movement. (NAPWA was dominated by white middle-class gay men at the time, and the organisation's work reflected this bias.<sup>39</sup> Achmat and Heywood, supported by NAPWA members like Mercy Makhramele and Prudence Mabele attempted to gain political control of NAPWA, but met fierce resistance from NAPWA leaders, including its director Peter Busse and the chair of its board, Mary Crewe.<sup>40</sup>)

Despite the failure to transform NAPWA, the campaign continued to make use of resources provided by existing civil society organisations, and also built up a network of supporters. (The TAC operated largely from the NCGLE offices at first,<sup>41</sup> and later made use of the resources of the AIDS Consortium, a consortium of HIV/AIDS organisations in Johannesburg.<sup>42</sup>). The founders took care to build relationships with civil society organisations, in particular the labour movement and churches. This approach was clearly rooted in earlier political experience and echoed the activities of the NCGLE under Achmat's leadership.

Says Achmat:

... That was also part of my training in the Marxist Workers' Tendency, of understanding that you need to construct the broadest coalition possible to deal with a particular issue... We understood from Marxism and the 'united front' tactics of Marxism that you constructed the broadest possible alliance under the leadership of the working class, and that's where I learnt my politics from. But also from the UDF, and the days before the UDF, the same approach...<sup>43</sup>

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<sup>39</sup> Quarraisha Abdool Karim argues that there wasn't a true representative structure for people living with HIV/AIDS in South Africa at the time. She tells of a meeting with a NAPWA group involved in organising an international GNP+ meeting in South Africa in 1995, consisting of a group of about eight men led by Shaun Mellors. She asked them why there were no women in the delegation. After this, women like Mercy Makhramele and Prudence Mabele started joining the meetings. (Interview, Q. Abdool Karim, 09/06/2008.)

<sup>40</sup> Interview, Achmat, 30/04/2008.

<sup>41</sup> Interview, Achmat, 30/04/2008.

<sup>42</sup> Interview, Ekambaram, 11/01/2008.

<sup>43</sup> Interview, Achmat, 30/04/2008.

Some of the new organisation's most reliable allies became Anglican and Catholic Church leaders, COSATU<sup>44</sup> and a number of NGOs like the Children's Rights Centre and others. The TAC has been at great pains to cultivate and sustain its alliances. In fact, until recently its constitution provided for representation on its National Executive Committee for various 'sectors,' including labour, the faith-based sector, women's sector and PWAs<sup>45</sup> (TAC, 2007).

It is unlikely that the activists would have been able to establish alliances with the labour movement (the Congress of South African Trade Unions is a key ally) had it not been for the Struggle background of many of the early TAC activists (who would have lacked credibility with trade union leaders). Heywood acknowledges this: "Zackie in particular, and myself to a lesser extent, were known before TAC, so quite a lot of the people that we encountered in the early days through TAC didn't see us as Johnny-come-latelies who had suddenly arrived on the scene. They knew us from our involvement before, and trusted us from our basic credentials. . . ."<sup>46</sup> But building the alliances was a deliberately executed strategy:

. . . from the very beginning we made a point of involving these organisations in TAC so that they could assess for themselves the bona fides of TAC because they had been involved in trying to put the thing together.

...

And you have to invest in these relationships. Very deliberately I keep contact with Vavi [General Secretary of COSATU], with Madisha [President of COSATU at the time] and so on. Even when we don't need them or they

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<sup>44</sup> The Congress of South African Trade Unions is the largest trade union federation in South Africa, and was responsible for a significant proportion of internal anti-apartheid mobilisation during the second half of the 1980s. It is largely black, traditionally ANC-aligned and now a member of the 'tripartite alliance with the ANC and the South African Communist Party. The TAC has good relationships also with the other two trade union federations in South Africa, FEDUSA (less radical and with a greater proportion of white members) and NACTU (traditionally Pan Africanist Congress-aligned with a more 'Africanist' ideological approach). However, the TAC's 'struggle heritage' and personal histories of its founders, as well as the desire to build the broadest possible front made for a more natural and closer relationship with COSATU. That relationship was both reflected in and facilitated by the Theodora Steele's (a senior COSATU leader) status as a long-time and respected TAC NEC member and her close relationship with Achmat.

<sup>45</sup> Person Living with HIV/AIDS

<sup>46</sup> Interview, Heywood, 17/12/2007.

don't need us, we talk to them, keep them in the picture so that there's a kind of thread that runs through the years.<sup>47</sup>

This is of course not to suggest that there have not been disagreements or tensions in these alliances. Rather, the point is that sufficient mutual trust and understanding had been established so as to survive those tensions. As already mentioned, the TAC defied COSATU's wish that it not embark on civil disobedience in 2003 (a campaign which COSATU did not endorse).<sup>48</sup> An earlier example was when TAC activists illegally imported generic fluconazole from Thailand in contravention of Pfizer's patent in 2000 (the Christopher Moraka Defiance Campaign). Achmat recounts how he received a message while already in Thailand that COSATU had requested him not to bring back the drugs (an "explicit instruction from the COSATU reps on our NEC"). He reports thinking "it's about loyalty to people who are dying without treatment"<sup>49</sup> and defied the instruction. According to Heywood, consistently acting in a principled fashion is what builds the trust that allows the alliances to survive such tensions.<sup>50</sup>

The XIII International AIDS Conference, held in July 2000 in Durban, is widely remembered as a turning point in the global AIDS response, with the moral imperative of wider availability of antiretroviral drugs taking centre stage at the conference.<sup>51</sup> A number of factors contributed to this: the impact of speeches by former South African president Nelson Mandela, teenage activist Nkosi Johnson and HIV-positive judge Edwin Cameron,<sup>52</sup> the fact that the conference was held for the first time in a developing country, but also the visibility of activists and the appeal they made for

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<sup>47</sup> Interview, Heywood, 17/12/2007.

<sup>48</sup> Heywood indicates that there were different positions within COSATU, with some leaders privately supporting the campaign, while others were deeply opposed to it (interview, 17/12/2007).

<sup>49</sup> Interview, Achmat, 30/04/2008.

<sup>50</sup> Interview, Heywood, 17/12/2007.

<sup>51</sup> Interviews, Gonsalves, 20/12/2007; S. Abdool Karim, 09/06/2008; Coovadia, 10/06/2008.

<sup>52</sup> In his speech, Cameron drew a sharp contrast between his own situation as a wealthy African who is able to afford life-saving treatment and the millions of AIDS patients in Africa condemned to death by the fact that they cannot do so, saying:

Amidst the poverty of Africa, I stand before you because I am able to purchase health and vigour. I am here because I can pay for life itself. To me this seems a shocking and monstrous iniquity of very considerable proportions - that, simply because of relative affluence, I should be living when others have died; that I should remain fit and healthy when illness and death beset millions of others. (Cameron, 2000)

treatment access.<sup>53</sup> The Treatment Action Campaign organised a ‘Global March for HIV/AIDS Treatment,’ attended by several thousand protesters and actively supported by a wide range of local and international organisations. The march was the point where TAC started garnering wide international attention and was the most significant public action yet for the young movement.

The TAC drew heavily on its civil society networks, particularly its extensive links within South African trade unions, NGOs and CSOs to mobilise support for the march and its demands.<sup>54</sup> Banners of many organisations not directly involved in the field of AIDS were carried prominently by the marchers.<sup>55</sup> While the principal focus of mobilisation was local,<sup>56</sup> the activists also drew on (relatively new) links with international activists to mobilise support for the march. It was endorsed by at least 258 organisations from across the world, activist organisations, NGOs, academic groupings and trade unions from countries like the US, Canada, the UK and Europe, Bolivia, Argentina, Chile, Brazil, Malaysia, Thailand, Bangladesh, Mexico, Senegal, Kenya, Zimbabwe and Namibia, as well as many from South Africa (Health GAP Coalition, 2000). American activist organisations — principally Health GAP, ACT UP Philadelphia, Treatment Action Group (TAG) and Gay Men’s Health Crisis (GMHC) — actively mobilised for the Global March in the weeks leading up to the conference, issuing appeals for support, press releases and setting up a website with campaign materials in English, French and Spanish.<sup>57</sup>

According to prominent international AIDS activist Gregg Gonsalves (working for the New York-based TAG at the time), the Durban conference was a galvanising moment for the international treatment access movement, with many US-based groups (like the AIDS Healthcare Foundation) diversifying their programmes “based on political solidarity” with the TAC and patients in the developing world.<sup>58</sup> For American activists, the Global March explicitly linked back to the political marches at earlier

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<sup>53</sup> Interview, S. Abdool Karim, 09/06/2008.

<sup>54</sup> Interview, Heywood, 10/01/2008.

<sup>55</sup> See <http://www.tac.org.za/photos/durb1.jpg>.

<sup>56</sup> Interview, Heywood, 10/01/2008.

<sup>57</sup> The website is no longer active, but can be viewed on the Internet Archive at <http://web.archive.org/web/20000815095001/http://durban2000march.org/>

<sup>58</sup> Interview, Gonsalves, 20/12/2007.

conferences (e.g. San Francisco in 1990<sup>59</sup>) and American activists “reconnected to their own anger” from earlier struggles (that had largely dissipated as treatment became widely available in the US), but Gonsalves attributes the greatest impact to the “vibrancy” and “political culture” of the TAC, which ignited the international activist movement.<sup>60</sup>

From this point onward, the TAC and its leaders played an increasingly central role in the international network of activists at the heart of the global treatment access movement, as the African epidemic became the focus of American and European activists. As Smith and Siplon have argued:

The protest march was notable not only in demonstrating the ability of the South African AIDS activist Treatment Action Campaign (TAC) to mobilize thousands of grassroots activists from deeply impoverished communities . . . [but also to] work within the global treatment activist movement that had furnished organisations and individuals that had supported TAC in this project. (Smith and Siplon, 2006:81–82)

The most important achievement of TAC in organising the action was perhaps in its ability to connect the widely divergent social spheres of South African communities most affected by HIV/AIDS (its grassroots activists consist largely of poor and unemployed Africans, primarily women), the South African workers’ movement, transnational social justice movements, aid-oriented NGOs (such as MSF) and American AIDS activists rooted in the militant activism and the service response mobilised in urban gay communities in the United States during the 1980s.

To be sure, TAC leaders like Achmat had recognised early on that a South African campaign for access to antiretroviral treatment could not succeed without a global campaign, not so much to exercise pressure on the South African state (through the so-called ‘boomerang effect’) as to address impediments that exist at the global level, such as intellectual property provisions in the international trade regime. Achmat credits Eric Goemaere of MSF with helping him see this.<sup>61</sup> Goemaere came to South Africa in 1999

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<sup>59</sup> The sixth International AIDS Conference was held in June 1990 and was the focus of significant activist mobilisation, including a march and a boycott organised in response to US visa restrictions on HIV-positive travellers (see, for example, Orkin, 1990).

<sup>60</sup> Interview, Gonsalves, 20/12/2007.

<sup>61</sup> Interview, Achmat, 16/05/2008.

and later set up the first public sector ART programme in Khayelitsha outside Cape Town in partnership with the TAC. At Goemaere's instigation, Achmat attended an MSF conference on access to medicines in Amsterdam in late 1999 at which he met activists already active on intellectual property rights issues, notably Jamie Love and Thiru Balasubramaniam from Consumer Project on Technology (CPT, now Knowledge Ecology International) as well as American AIDS activists Asia Russell and Paul Davis from ACT UP Philadelphia. After the conference, Achmat and other TAC activists maintained contact with these international activists — principally by email, including through the IP-Health mailing list moderated by Love.<sup>62</sup>

The TAC later made use of these contacts in mobilising international support during the PMA case described earlier, with activists, for example, targeting the Gore presidential campaign in order to end the US Government's measures against South Africa and in support of the pharmaceutical industry (see Smith and Siplon, 2006). Love and CPT also assisted during a complaint laid by the TAC with the South African Competition Commission over excessive pricing practices by Glaxo SmithKline (GSK), which led to a settlement in which GSK agreed to voluntarily license its products to generic manufacturers.<sup>63</sup> The transnational activist network to which the TAC leaders belonged was decisive in changing the intellectual property framework which was hampering access to antiretroviral drugs. Particularly the TRIPS agreement (Trade Related Intellectual Property Rights), which required WTO members to implement patent provisions, including on pharmaceuticals, was an impediment to the availability of generic ARVs — seen as essential for greater access given the extremely high prices of the drugs charged by originator companies at the time (Berger, 2002; 't Hoen, 2002). An important milestone was the Doha Declaration (adopted during the WTO Ministerial Meeting in Doha in November 2001), which recognised the right of developing countries experiencing public health emergencies to override intellectual property rights on pharmaceutical products.<sup>64</sup> While the Brazilian government took

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<sup>62</sup> Interview, Achmat, 16/05/2008. The IP-Health list has a public archive available on the Internet (see <http://lists.essential.org/pipermail/ip-health/>). A review of the archive confirms that Achmat was one of its more active members during this period.

<sup>63</sup> Interview, Berger, 16/12/2007.

<sup>64</sup> Specific measures available include compulsory licences and parallel importation. The full text of the declaration is available at <http://docsonline.wto.org/imrd/directdoc.asp?DDFDocuments/t/WT/Min01/DEC2.doc>

the lead in pushing for the adoption of the declaration, and MSF's international campaign was important in creating a climate in which developed countries could not oppose it, Achmat argues that the Doha declaration could not have occurred without the PMA case and the attention it focused on the relationship between intellectual property rights and access to AIDS treatment thanks to the TAC and its allies' campaign.<sup>65</sup>

While the building of an international solidarity network was therefore driven by strategic considerations, personal connections were important even here. Early in 2000, Achmat visited the United States and was put in touch with Gregg Gonsalves and Mark Harrington of the Treatment Action Group in New York by Loring McAlpin, a mutual friend who had met Gonsalves and Harrington through ACT UP New York.<sup>66</sup> Joint TAC/TAG 'treatment literacy' workshops were held early in 2000 in Johannesburg and Cape Town and included American and South African activists as well as medical professionals like Dr Herman Reuter. According to Gonsalves, it is possible to distinguish between two "generations" of American activists with whom the TAC established links around the time of the Durban conference. The "first generation" — activists who had been active in ACT UP and the American AIDS activism of the 1980s (including people like Gonsalves and Harrington) — were at the time less active in international struggles. A "second generation" of activists, which included people like Asia Russell and Paul Davis of ACT UP Philadelphia and Alan Berkman of Health GAP had a greater interest in global treatment access and a better understanding of the intellectual property and trade policy issues.<sup>67</sup> While TAC leaders had met the 'second generation' activists first, they ended up forming closer relationships with 'first generation' activists, mediated to a significant extent by Gonsalves. Gonsalves has remained the most important link between TAC leaders and American activists, and more recently played a central role in forging relationships between TAC activists and Asian, African and Eastern European activists, for example organising the International Treatment Preparedness Summit in 2003, out of which the Pan African Treatment Access Movement — an informal network of African AIDS activists — developed. The closer relationship may in part be explained by

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and an explanation of the declaration from

[http://www.wto.org/english/tratop\\_e/dda\\_e/dohaexplained\\_e.htm](http://www.wto.org/english/tratop_e/dda_e/dohaexplained_e.htm).

<sup>65</sup> Interview, Achmat, 16/05/2008.

<sup>66</sup> Interview, Gonsalves, 20/12/2007.

<sup>67</sup> See Smith and Siplon (2006). Interview, Gonsalves, 20/12/2007.

the strong personal bond that developed between, in particular, Achmat and Gonsalves,<sup>68</sup> and is probably also related to greater personal identification resulting from shared experiences, including gay activism and first-hand experience of the HIV epidemic (like Achmat, many ‘first-generation’ activists like Gonsalves are HIV-positive).<sup>69</sup>

A further network that was significantly strengthened during and after the Durban AIDS Conference is the activist-scientist networks that helped TAC activists establish their credibility in scientific debates and contributed to the politicisation of scientists. This is the subject of a separate paper and will not be described in detail here. A key moment was when South African president Thabo Mbeki shocked delegates at the Conference by citing poverty (as opposed to HIV) as a leading cause of death and stating “we cannot blame everything on a single virus,” (Mbeki 2000, cited in Natrass, 2007:68), which resulted in scientists aligning themselves with the activist movement.<sup>70</sup> For some scientists like Prof Hoosen Coovadia, the denialist attack on science and evidence-based health policy did more to politicise their thinking than the morality of treatment access.<sup>71</sup> Hundreds of leading AIDS scientists signed the Durban Declaration — addressed to President Mbeki and also published in *Nature*<sup>72</sup> — affirming the scientific consensus on the viral aetiology of AIDS. Gonsalves points also to Cameron and Mandela’s speeches at the conference as key moments in the ‘radicalisation’ of the scientific AIDS community.<sup>73</sup> But sustained political engagement by the scientific community from 2000 onwards is attributable to a significant extent to their participation in the emerging network of influence involving key South African and American activists (as well as, especially later, from elsewhere in Africa, Asia and Europe).<sup>74</sup>

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<sup>68</sup> See Smith and Siplon (2006). Interview, Gonsalves, 20/12/2007.

<sup>69</sup> Achmat himself mentions being personally affected by HIV (as opposed to seeing it as just another issue where, e.g., intellectual property rights are relevant) as a factor in the rapport between ‘first generation’ activists and TAC activists. (Interview, Achmat, 16/05/2008.)

<sup>70</sup> Interview, S. Abdool Karim, 09/06/2008.

<sup>71</sup> Interview, Coovadia, 10/06/2008.

<sup>72</sup> *Nature* 406, 15–16 (6 July 2000) (DOI: 10.1038/35017662). It can also be accessed on <http://www.aidstruth.org/the-durban-declaration.pdf>.

<sup>73</sup> Interview, Gonsalves, 20/12/2007.

<sup>74</sup> These activist-scientist networks (particularly with respect to North American scientists) drew on strong linkages established earlier between activists like Gonsalves and Harrington and the scientific community during the late 1980s and early 1990s, when new drug development, testing and registration, participation in clinical trials, etc. were central (more so than pricing and intellectual property) to activist efforts to promote greater access to treatment. See Epstein (1996)

Leveraging these international networks has become an important strategy in the TAC's mobilisation since 2000, with international solidarity campaigns, including frequent calls for 'Global Days of Action', playing a significant role in, inter alia, the campaign to support the South African government during its dispute with pharmaceutical companies,<sup>75</sup> TAC's complaint over GlaxoSmithKline's pricing policies and its campaign to get the South African government to commit to a public sector antiretroviral treatment programme.

### **Illustrating networks of influence**

In Figure 1 below, I provide a simplified network diagram illustrating the most important links in the 'network of influence' around the Treatment Action Campaign. It should be noted that this is not intended to be an exhaustive network analysis, but merely to illustrate some of the points made in this paper.<sup>76</sup> For reasons of economy, certain organisations are included as nodes in the network (represented by diamonds in the diagram) even though the real unit of analysis is individuals (represented by rounded squares in the diagram).

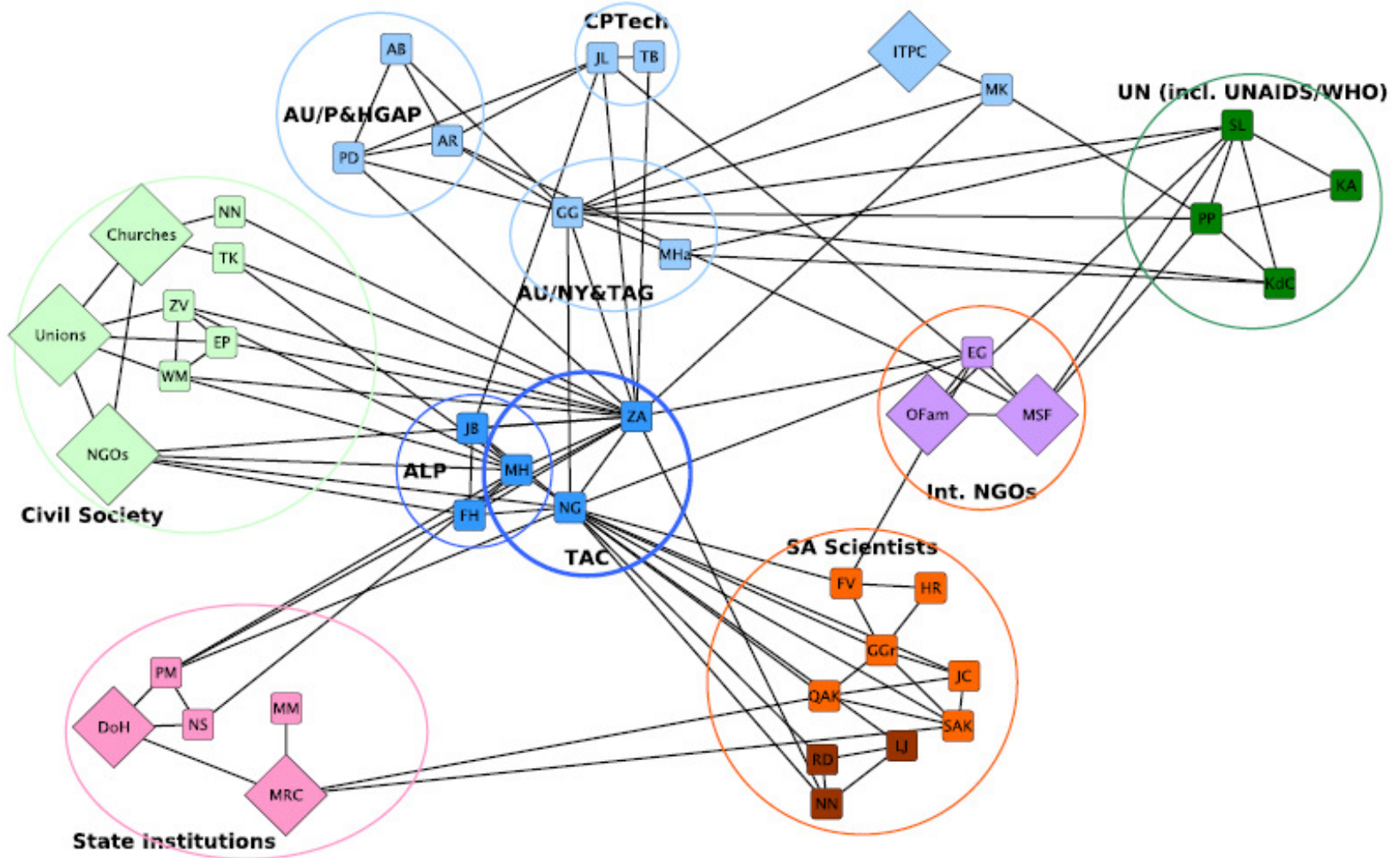
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and the first half of Smith and Siplon (2006) for excellent overviews of this period of American treatment activism. Gonsalves, for example, was a member of ACT UP New York's Treatment and Data Committee from 1990 and Mark Harrington (Gonsalves's partner for some years) from even earlier. The Committee worked to open up scientific structures, with members for example crashing an ACTG meeting in 1989, prompting it to set up a Community Constituency Group (Epstein, 1996:286).

<sup>75</sup> Interview, Heywood, 10/01/2008.

<sup>76</sup> The data available to me is not comprehensive enough to allow an exhaustive network analysis. Furthermore, the nodes included in the network diagram reflect my own perceptions and assumptions as well as those of informants; trying to deduce the relative importance of nodes based on the network structure as reflected in the diagram therefore implies a certain circularity. Nevertheless, the exercise is useful if only for illustrative purposes.

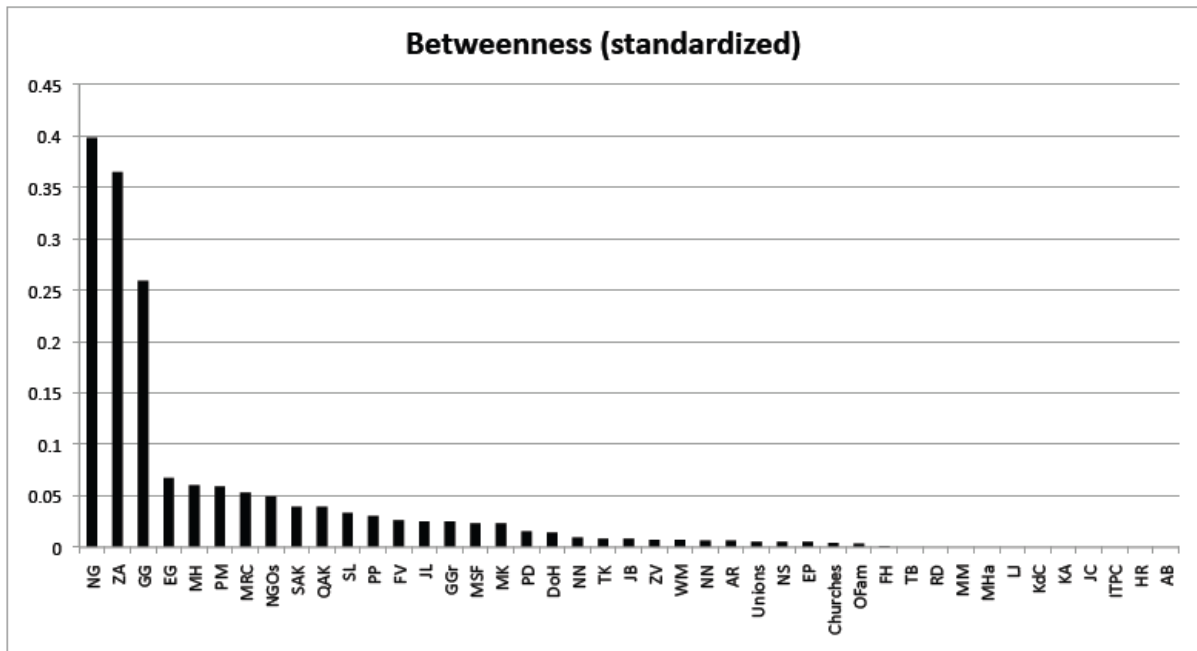
Figure 1: Network of influence around the Treatment Action Campaign





What is also notable, as can be seen in Figure 3, is that very few nodes take on brokerage roles to any significant extent, underscoring the point that a small number of individuals are very important in constructing networks of influence.

*Figure 3: Nodes ranked according to ‘betweenness centrality’*



### **Conclusion: From networks to coalitions**

As argued in the review of theoretical approaches to AIDS activism (Grebe, 2008), networks should be understood in a more inclusive and dynamic sense than that of ‘transnational activist networks’ (see Keck and Sikkink, 1998). My alternative — ‘transnational networks of influence’ — includes the sort of networks that Keck and Sikkink describe as a critical component, but expands the notion to include actors such as scientific communities, diplomats and bureaucrats active in international organisations and even extending into the institutions of the target state. I have also argued for the importance of individuals, of personal and informal relationships and of networks that predate formal activist activity.

These arguments are supported by the evidence from the history of AIDS activism in South Africa. It has been shown in this paper that the founders of TAC drew extensively on personal networks to mobilise resources for the movement and also built activist and solidarity networks in order to mobilise support and influence. It is also clear that the history of AIDS activism is intimately tied to a number of key personalities and that even where ‘structural’ patterns can be discerned (such as the utilisation of transnational networks of influence) these were often made possible by the unique connectedness and unusual capabilities of those individuals.

But in order to understand the impact of the Treatment Action Campaign, we must look beyond networks — which functions mainly to mobilise resources (including symbolic and informational resources) to the emergence of coalitions based on consensus. The TAC’s campaigns were informed by a desire to produce a ‘moral consensus’<sup>78</sup> on treatment access and in my view succeeded in establishing an AIDS treatment coalition (despite continuing obstruction from sections of the state, including President Mbeki and his Minister of Health) built on such a moral consensus.

Despite the visibility of mobilisation in the form of street protests and (on a limited number of occasions) direct action and civil disobedience, the strategy does not seem primarily to be to compel a change of course in its adversaries through direct pressure, but rather to drive home its moral claims. Protest action is then but one component in a larger strategy aimed at building a moral consensus in society and thereby exerting both direct and indirect pressure. This is evident from its tendency to pursue its campaigns through a variety of strategies, often aimed at legitimating a central moral claim rather than simply exerting pressure. For example, its campaigns against “excessive pricing” and “patent abuse” by pharmaceutical companies were anchored by strong moral appeals. It mobilises alliances with other civil society actors — particularly those with a high degree of popular legitimacy — and frames its moral claims by a ‘rights-based discourse’ that enjoys wide legitimacy in South Africa and internationally. It is particularly powerful in the South African context where the human rights framework contained in the Constitution is the outcome of a long popular struggle. (This human rights orientation arguably found its most compelling expression in the

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<sup>78</sup> As mentioned earlier, this formulation is derived from Achmat’s own statements on the subject.

litigation by which the TAC forced the South African government to make PMTCT widely available.) The fact that it can claim to speak for a broad social alliance, rather than simply on behalf of those who are HIV-positive, significantly enhances its moral authority. On several occasions its opponents, notably the government, have sought to attack its credibility,<sup>79</sup> a strategy that has been frustrated by the high degree of legitimacy that the TAC has been able to achieve.

The TAC's attempts at constructing moral consensus — a process of 'framing' — is itself transnational in character and operates through its wider networks of influence. These include both the international media and activist networks that in turn connect the TAC's struggle to national public spheres and to opinion leaders in those countries. As Olesen (2006:7) points out, the very 'problem construction' of the international campaign for access to HIV/AIDS treatment is a transnational framing process in that it pushes a local and national problem into "the court of transnational public opinion."

The networks of influence that formed the basis of the emerging AIDS treatment coalition extended into the state and ruling party. A number of ANC parliamentarians were sympathetic to the TAC (or at least open to its messages) even at the height of government denialism, including Barbara Hogan, Pregs Govender, Andrew Feinstein and Essop Jassat.<sup>80</sup> Mark Heywood maintained a cordial relationship with Nono Simelela (Chief Director: HIV/AIDS during the period of greatest conflict between TAC and the government)<sup>81</sup> and she even attended a conference organised by the organisation.<sup>82</sup> The President of the Medical Research Council, Malegapuru Makgoba, displayed a high degree of independence from the government, and at times aligned himself with

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<sup>79</sup> Mbeki and his circle apparently viewed the TAC as a front for the pharmaceutical companies in a CIA-supported campaign to promote the view that HIV causes AIDS. In an infamous caucus meeting of ANC parliamentarians in September 2000, Mbeki is reported to have said, "The Treatment Action Campaign is leading the statements and vitriol against one. They are funded by pharmaceutical companies in the US. They also say they can't just dismiss Mbeki's views" (Feinstein, 2007:125). This allegation has resurfaced repeatedly, and has also been made by AIDS denialists like Antony Brink, and the Rath Health Foundation.

<sup>80</sup> Personal communication with Zackie Achmat. Also see Feinstein (2007).

<sup>81</sup> Interviews, Heywood, 18/12/2007 and 10/01/2008.

<sup>82</sup> See Lewis (2003).

TAC.<sup>83</sup> The South African state did not operate as a monolithic entity which resisted or yielded to external pressure. Confusion and reversals in South African AIDS policy were arguably the result of shifting patterns of power and influence within state, ruling party and civil service institutions.<sup>84</sup> Rather, the state mirrored within itself the complexities and tensions of the emerging AIDS treatment coalition.

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<sup>83</sup> For example, during a controversy over the MRC's 2001 report into mortality (Dorrington et al., 2001), which the government tried to suppress, he refused to withdraw the report, despite intense pressure (see Nattrass, 2007:92-93).

<sup>84</sup> For example, the Treasury increased the budget for HIV/AIDS programmes substantially in the 2003/2004 budget — apparently with a view to funding a national antiretroviral therapy programme — but well before the cabinet had agreed to such a roll-out and apparently while the President and Minister of Health maintained their staunch opposition to such a programme. Even the decision to implement the programme taken in August of that year is widely considered a cabinet revolt (see, for example, Nattrass, 2007) of which the Minister was not supportive. Despite the antiretroviral treatment programme, the Minister continued to express scepticism about ARVs and to support alternative and untested “treatments” (see Geffen, 2006). A rapprochement occurred between activists and the government in 2006 during the Minister's prolonged illness under the leadership of Deputy Minister of Health Nozizwe Madlala-Routledge with the support of Deputy President Phumzile Mlambo-Ngcuka (often described as a “palace coup” in the media) which saw the formulation of a new National Strategic Plan for HIV/AIDS that included ambitious targets for the expansion of antiretroviral treatment and other policies to which the Minister is known to be hostile. Following her return, the progress was rapidly reversed and tensions flared up, culminating in the dismissal of the Deputy Minister by Tshabalala-Msimang's patron President Thabo Mbeki.

## List of interviewees

- 1 *Quarraisha Abdool Karim* (Director: HIV/AIDS, South African Department of Health 1994-1995, Centre for the AIDS Programme of Research in South Africa [CAPRISA]): Durban, 9 June 2008.
- 2 *Salim Abdool Karim* (Director: CAPRISA): Durban, 9 June 2008.
- 3 *Zackie Achmat* (TAC founder, TAC Chairperson 1999-2008, former MWT member): Cape Town, 16 June 2007 (conducted by Raja Farah); Cape Town, 30 April 2008; Cape Town, 16 May 2008.
- 4 *Jonathan Berger* (Head of Research: AIDS Law Project, former partner of Zackie Achmat): Johannesburg, 16 December 2007.
- 5 *Deena Bosch* (TAC founding member and senior employee, former MWT member, longtime friend of Zackie Achmat): Cape Town, 26 November 2007.
- 6 *Hoosen (Jerry) Coovadia* (Former head of Paediatrics, University of KwaZulu-Natal; Chair: International AIDS Conference, Durban 2000; CAPRISA): Durban, 10 June 2008.
- 7 *Vuyiseka Dubula* (TAC Employee 2002-2008, TAC General Secretary 2008-): Cape Town, 18 April 2008.
- 8 *Sharon Ekambaram* (First TAC Gauteng provincial coordinator, former AIDS Consortium employee, Director: MSF Johannesburg, former MWT member, wife of Mark Heywood): Johannesburg, 11 January 2008.
- 9 *Nathan Geffen* (TAC National Manager 2001-2006, TAC Policy Communication and Research manager 2006-2008, TAC National Treasurer 2008-): Cape Town, 19 April 2008.
- 10 *Gregg Gonsalves* (Formerly of ACT-UP New York, Treatment Action Group and Gay Men's Health Crisis, now Director: AIDS & Rights Alliance Southern Africa): Cape Town, 20 December 2007.
- 11 *Andrew Gray* (Department of Pharmacology, University of KwaZulu-Natal, CAPRISA): Durban, 10 June 2008.
- 12 *Mark Heywood* (Director: AIDS Law Project, TAC National Treasurer 1998-2008, former MWT member, longtime friend of Zackie Achmat): Johannesburg, 17 December 2007; Johannesburg, 10 January 2008.
- 13 *Leigh Johnson* (Centre for Actuarial Research, University of Cape Town): Cape Town, 3 June 2008.
- 14 *Jack Lewis* (TAC founding member, former MWT member, former partner of Zackie Achmat, Director: Community Health Media Trust): Cape Town, 24 November 2007.
- 15 *Mandla Majola* (TAC Khayelitsha District Coordinator, former TAC

- National Organiser): Cape Town, 21 April 2008.
- 16 *Pholokgolo Ramothwala* (Former TAC Gauteng provincial coordinator, Corporate Relations Manager: LoveLife): Johannesburg, 11 January 2008.

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