# ANNUAL REPORT 2017

Prince Claus Chair **development and equity** 

THE INTERNATIONAL INSTITUTE OF SOCIAL STUDIES OF ERASMUS UNIVERSITY ROTTERDAM AND UTRECHT UNIVERSITY WILL ALTERNATELY APPOINT AN OUTSTANDING YOUNG ACADEMIC FROM A DEVELOPING COUNTRY TO THE PRINCE CLAUS CHAIR, FOR THE ADVANCEMENT OF RESEARCH AND TEACHING IN THE FIELD OF DEVELOPMENT AND EQUITY. annual Report 2017

## "PROFESSOR SULEMAN'S RESEARCH WILL BE AS EAGERLY AWAITED HERE AS IN SOUTH AFRICA"

Through their work, the holders of the Prince Claus Chair do not only provide us with a window on the global south, their research also serves to hold up a mirror to the global north. Take the example of our current chair holder, the South African Professor. Fatima Suleman. With her study of the affordable and equitable access to bio-therapeutics she draws our attention to one of the most important prerequisites for the development of low- and middle-income countries. A fair distribution of healthcare is a pressing issue. But, as Professor Suleman subtly noted in the inaugural lecture she gave in May 2017, the problem is not limited to developing economies. Many of her observations apply just as much to higherincome countries. In the Netherlands too, medicine prices are going through the roof. I suspect that the outcomes of Professor Suleman's research will be as eagerly awaited here as in her home country.

It is beyond doubt that with Professor Suleman we have appointed to the chair a scholar who has shown that she is more than fit for the job. First of all, she can rightfully be called a specialist in her field. She brings with her a tremendous amount of knowledge and experience and she has the level of confidence necessary to shed new light on this complicated healthcare problem. In addition, Professor Suleman goes about her research with dedication and enthusiasm. A case in point was her eager contribution to the academic courses offered in 2017 within the Utrecht Summer School programme by Utrecht University and partnering institutions. Professor Suleman has also tirelessly acted as a representative of Utrecht University at healthcare conferences across Europe, sparking international knowledge exchanges and boosting cross-border academic networks. On top of it all, as an acknowledgement of her achievements, she has recently been offered the position of Professor at the University of KwaZulu-Natal, South Africa. Not surprisingly, catching up with Professor Suleman for our regular progress meetings has been no simple task, but I am certainly not complaining. It is exactly these interactions with students, scholars and other professionals that the Prince Claus Chair aims to establish and expand.

As Professor Suleman does now and Professor Saradindu Bhaduri did before her, all holders of the Prince Claus Chair observe the challenges of development and equity from their own scientific perspective. Successively, they add pieces to the puzzle. A further highly essential piece will be added by Professor Ali Bilgiç, who will hold the chair from 2017 to 2019.

Showing the same degree of eagerness that characterised his predecessors, Professor Bilgic, who is a senior lecturer at Loughborough University in the United Kingdom, is going to carry out research in the area of migration. He is planning to focus on the human security approach to migration. In this minefield of heated debates and growing polarisation, I was pleased to find in Professor Bilgic, a scientist in the truest sense. He is a man who steers clear of the emotions of politics and instead focuses on sheer rational research. We have appointed to the chair a young man with an outstanding record of service. I am looking forward to following his progress as he explores a world in which some countries seem unable to offer their citizens a safe home, let alone economic and intellectual development, and in which other countries struggle to accommodate waves of people hoping to build up a more dignified and meaningful life. This is not, I would like to add, merely a problem in Europe, but also in Africa and the Middle East.

As Ali Bilgiç takes the baton from Fatima Suleman, we are in a somewhat festive mood. 2018 marks our fifteenth anniversary and we plan to celebrate the occasion fittingly. As the Prince Claus Chair matures, we are turning to the younger generation for inspiration for our future course. Let me close by thanking our chair holders past and present, but also, by extending a warm advance welcome to their future successors.

Professor Louise J. Gunning-Schepers Chair of the Curatorium



Professor Louise J. Gunning-Schepers is a Distinguished University Professor of Health and Society at the University of Amsterdam. Her position as chair of the Curatorium is in a personal capacity.

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THE PRINCE CLAUS CHAIF

## OBJECTIVES OF THE PRINCE CLAUS CHAIR

## PRINCE CLAUS, THE INSPIRATION FOR THE CHAIR

The objective of the Prince Claus Chair is to continue the work of His Royal Highness Prince Claus of the Netherlands (1926-2002) in development and equity, by establishing a rotating Academic Chair.

Since the Chair was established in December 2002, Utrecht University and the International Institute of Social Studies of Erasmus University Rotterdam have alternately appointed an outstanding young academic from a developing country to the Prince Claus Chair. The objective is to advance research and teaching in the field of development and equity. Candidates for the Chair are nominated by a Curatorium, under the chairmanship of Professor Louise J. Gunning-Schepers. H.M. Queen Máxima of the Netherlands, Honorary Patron of the Prince Claus Chair H.M. Queen Máxima of the Netherlands served as the first chair of the Curatorium of the Prince Claus Chair from when it was founded in 2003. In May 2014 she symbolically handed over an African chief's staff to the incoming chair, Professor Louise J. Gunning-Schepers, and graciously agreed to assume the role of Patron. As Patron, Queen Máxima remains associated with, and deeply committed to, the work of the Prince Claus Chair on issues of development and equity.



His Royal Highness Prince Claus of the Netherlands was strongly committed to development and equity in North-South relations. Through his work, his travels and his personal contacts, he gained a deep understanding of the opportunities for, and the obstacles facing, equitable development. He was tireless in his work for development and equity throughout the world, bringing people together to solve problems and make the most of opportunities. His knowledge, his accessibility and his personality all made an important contribution to his work. As a result, he was – and remains – a source of inspiration to many.

In 1988, Prince Claus received an Honorary Fellowship from the International Institute of Social Studies (ISS) 'in recognition of his continued insistence on the importance of reducing the differences between the rich and the poor in national and international fora, while emphasising the human dimension of this process and not only that of international policy and strategy.' At the official ceremony for the award of the Fellowship, Prince Claus gave an acceptance speech stating his views on development and equity in the form of 23 propositions.

The establishment of the Prince Claus Chair attests to the deep respect and appreciation of the academic community of Utrecht University and the ISS for Prince Claus as a person, for his work, and for his commitment to and authority in the field of development and equity throughout the world.

Prince Claus was born Claus von Amsberg in 1926, in Dötzingen (Hitzacker), Niedersachsen. He studied at the University of Hamburg in the Faculty of Law and Political Science (1948-1956), after which he worked at the German embassy to the Dominican Republic and as Chargé d'Affaires to the Republic of the Ivory Coast. From 1963 to 1965, he worked at the Ministry of Foreign Affairs in Bonn, in the Department of African Economic Relations.

After his marriage to Her Royal Highness Princess Beatrix of the Netherlands in 1966, Prince Claus focused his efforts on development cooperation. He was appointed as a member of the National Advisory Council for Development Cooperation (Nationale Adviesraad voor Ontwikkelingssamenwerking, NAR). In addition, he was Chair of the National Committee for Development Strategy (Nationale Commissie voor de Ontwikkelingsstrategie), a position he held from 1970 to 1980, and Special Advisor to the Minister of Development Cooperation. In 1984, he was appointed Inspector General of Development Cooperation. To commemorate the Prince's 70th birthday, the Dutch government established the Prince Claus Fund for Culture and Development (Prins Claus Fonds voor Cultuur en Ontwikkeling), of which Prince Claus was Honorary Chair. The objective of the Fund is to increase cultural awareness and promote development.

## CHAIR OF SEARCH

#### COMMITTEE

## PROFESSOR ELLEN MOORS: "FATIMA SULEMAN WILL PROVE AN OUTSTANDING CHOICE"

"When the Prince Claus Chair is on the lookout for a new scholar to hold the chair, one of the key requirements is that candidates focus on a subject that has not been addressed by any of their predecessors. With the growing list of chair holders, this makes the search committee's task an increasingly challenging one. More so, given the additional prerequisites that candidates are young yet experienced and that they know their way in science as well as in policy-making and societal outreach.



**Ellen Moors** is Professor of Sustainable Innovation at Utrecht University and Chair of the Prince Claus Chair Search Committee 2016-2018. This time around, we set about trying to find someone who would be able to help the Utrecht Centre for Affordable Biotherapeutics achieve its goal: to improve global health by enabling the sustainable production of high quality and affordable bio-therapeutics that are accessible to patients in low and middle-income countries.

That is when Fatima Suleman came into the picture.

A researcher from South Africa, Professor Suleman's main area of interest is the pricing of drugs for diseases which cause huge suffering. Like us, she believes that affordability and equitable access to therapeutics are crucial to the advancement of global health.

What is more, Professor Suleman is not only well-informed about the medicine pricing system in her home country, she has also built up an impressive network of contacts in pharmaceutical science and policy circles around the world, as well as in the World Health Organisation (WHO).

It is the combination of her vast knowledge and this collaborative approach, combined with her unrelenting optimism, which makes me convinced that Fatima Suleman will prove an outstanding choice for the Prince Claus Chair."



CHAIR HOLDER

2016-2018

## PROFESSOR FATIMA SULEMAN

Fatima Suleman is a Professor of Pharmaceutical Sciences at the University of KwaZulu-Natal in South Africa. She also has ties to Drake University in the United States. Her main areas of interest are equity and access to medicines, and pricing and reimbursement policies. One of her research projects is about the pricing of medicines for chronic conditions which cause huge suffering. Professor Suleman is the Chair of the National Pricing Committee for Medicines in South Africa and a member of the WHO Expert Committee on the Selection and Use of Essential Medicines. She has been appointed by Utrecht University as holder of the Prince Claus Chair 2016-2018. On 16 May 2017 Professor Suleman gave her inaugural address in the historic Utrecht University Hall in the presence of members of the Curatorium of the Prince Claus Chair and many distinguished guests. In her capacity of chair holder she is conducting research into affordable (bio)therapeutics in collaboration with scholars at the Utrecht Centre of Excellence for Affordable Biotherapeutics and the WHO Collaborating Centre for Pharmaceutical Policy and Regulation.









ABSTRACT OF THE

## AFFORDABILITY AND EQUITABLE ACCESS TO MEDICINES FOR PUBLIC HEALTH

The Sustainable Development Goals (SDGs), adopted in September 2015 by the member states of the United Nations, recognise that equitable access to affordable, quality-assured essential medicines is a crucial step in achieving universal health coverage. Many factors affect access to medicines. Affordability is one dimension of access. Affordability becomes a particularly serious problem when medicines are needed for chronic conditions, including non-communicable diseases (NCDs). However, to date, there is no easy and quick method of assessing affordability. It is also important to note that affordability will differ from health system to health system, and from country to country. We need to find more ways to measure affordability within a shorter timeframe, especially within a policy environment. This is not a topic for low and middle-income countries alone. The topic of access to medicines was debated by the European Parliament in plenary in 2014 and 2015. The last session focused on the very high prices for certain life-saving medicines such as sofosbuvir for the treatment of hepatitis C, and certain cancer medicines. It also raised questions about the rationale behind such prices and the transparency of this rationale. There is a need for studies to look at alternate models to fund R&D. The Global Fund, through UNITAID, receives some of its funds from airline taxes or levies. Is it not possible to implement a similar approach for a fund for medicine R&D? Can proposed taxes on sugar and salt use in

foods and beverages not be directed (even as a small percentage) towards a fund for medicine R&D? If the research is publicly funded, should then these medicines not be priced affordably? Discussions would then need to revolve around what a 'fair' price for a medicine would be, so as to maintain research and development and supply, and not create shortages or market withdrawal. What constitutes a fair price? What are the components that need to be considered in the determination of a fair price? Should this differ between countries according to the income of the people in those countries? Medicine price discussions should focus on the 'reasonable bounds' of pricing. The price of a new essential medication should reflect how much it advances the practice of medicine and how it can achieve universal access as soon as possible. These are some of the areas of research that I would like to explore during my tenure: Which quick measure of affordability can be used by policymakers to assess the affordability of medicines for the population? Can a health system in a low- or middle-income country afford the medicines they put on their essential medicines' list? What are the strategies that families use to manage their expenditure on medicines, especially medicines for non-communicable chronic diseases. How much do they receive from the system, how much do they spend out-of-pocket, and what other coping mechanisms do they have? How transparent are pricing interventions to patients and do they see the benefits of these interventions, as they are the intended beneficiaries?





PERSONAL PROFILE

Professor Fatima Suleman works as a Professor of Pharmaceutical Sciences at the University of KwaZulu-Natal in South Africa.

#### CURRENT POSITIONS

#### November 2017 - to date

Professor of Pharmaceutical Sciences at the University of KwaZulu-Natal in South Africa

#### 2017 - 2021

Member of the World Health Organisation's (WHO) Expert Advisory Panel on Drug Evaluation.

#### 2016 - 2017

Member of an informal technical advisory group of the WHO's Fair Pricing Forum Project.

2014 - to date Chair of the National Pricing Committee in South Africa.

#### 2010 - to date

Member of the National Pricing Committee in South Africa.

#### 2009 - to date

Adjunct Assistant Professor at the College of Pharmacy and Health Sciences in the Department of Clinical Sciences (2009-2015) at Drake University in Des Moines, Iowa, United States of America.

#### PREVIOUS POSITIONS

#### January 2011 - November 2017

Associate Professor in Pharmaceutical Sciences at the School of Health Sciences, University of KwaZulu-Natal, South Africa.

#### January 2014 - March 2016

Member of National Essential Medicines' List for Adults Committee in South Africa.

#### 2009 - 2015

Member of the Medical Products Technical Task Team as well as the Procurement Task Team, appointed by the National Minister of Health of South Africa.

#### 2008 - 2012

National Executive Member of the Pharmaceutical Society of South Africa.

#### 2011 - 2012

Member of the WHO Pricing Policy Guideline Committee.

#### 1997 - 1998

Member of the South African Primary Health Care Essential Drugs' List Review Committee.

#### 1997 - 1998

Member of KwaZulu-Natal Province Essential Drug Programme Coordinating Committee in South Africa.



Bert Leufkens, Rianne van den Ham, PhD, Fatima Suleman and Dr. A.K. (Aukje) Mantel-Teeuwisse (Postdoc to PCC)

#### HONOURS AND AWARDS

#### 2017 to date

C2-rated researcher at the South African National Research Foundation (NRF).

#### 2006 to date

Numerous grants from the National Research Foundation, the University of KwaZulu-Natal, the Medical Research Council and the National Institute of Health in South Africa.

#### 2010

Distinguished Teachers' Award, awarded by the University of KwaZulu-Natal, South Africa, for her role in curriculum development and innovative teaching practices.

#### 2002 - 2004

Fulbright Scholar in the American scholarship program for international educational exchange for students, scholars, teachers, professionals, scientists and artists.



Lunch with ISS colleagues

#### ACTIVITIES AS HOLDER OF THE CHAIR

#### MEETINGS AND CONFERENCES

Since her appointment as chair holder, Professor Suleman has attended meetings and conferences throughout the world. Here is a selection of these activities.

#### 12 July 2017

Meeting with the Department of Pharmaceutical Affairs and Medical Technology, Dutch Ministry of Health, The Hague, The Netherlands.

#### 15 May 2017

Lunch with female professors and postdocs within the Department of Pharmaceutical Sciences, Utrecht University, The Netherlands.

#### 10 - 12 May 2017

WHO Fair Pricing Forum and Advisory Board Meeting, Amsterdam, The Netherlands.

#### 2 - 3 May 2017

WHO Expert Consultation on Improving Access to and Use of Similar Biotherapeutic Products, WHO, Geneva, Switzerland.

#### 6 April 2017

Meeting with sections within the Essential Medicines Programme at WHO, Geneva, Switzerland, together with Dr Aukje Mantel-Teeuwisse, Managing Director WHO CC for Pharmaceutical Policy and Regulation, Utrecht University and Gilles Forte.





A lecture given at the GH&TM course on September 6th, at 19.00-21.30 at the University Medical Center Utrecht, Green lecture hall

World Health Organization's Expert Committee on Selection and Use of Essential Medicines for 2017



Technical Expert to Malaysian Ministry of Health for Capacity building on price setting mechanisms and developing a framework for medicine price regulation

#### 21 March 2017

Participated in the PhD AOI class. Topic: 'Single vs. Multi Country Studies: Implications for (Extrapolation of) Study Results' with Dr Aukje Mantel-Teeuwisse, Utrecht University.

#### 27 - 31 March 2017

WHO Expert Committee on the Selection and Use of Essential Medicines, WHO, Geneva, Switzerland.

#### 14 March 2017

Meeting with Peter Stephens from IMS UK regarding collaboration in South Africa and with research, Utrecht University.

#### 10 - 11 January 2017

PhD Winter meeting/Examination Defence, Utrecht with Dr Aukje Mantel-Teeuwisse, Utrecht University.



#### PRESENTATIONS

During her term as chair holder professor Suleman has lectured and addressed audiences at various universities and organisations. Below is a selection of these presentations.

#### 30 November 2017

'South Africa's Experience with Managing Medicine Prices in the Private Sector', Access to Medicine Foundation, Amsterdam, The Netherlands.

#### 29 November 2017

'Access to Medicines in Low and Middle Income Countries: Obstacles and Opportunities, Developments over the Last Decade? ', mini symposium 'Access to Medicines, Global Issues and Global Solutions? ', UMCG, Global Health, University of Groningen, The Netherlands.

#### 21 - 23 November 2017

'Creating a balance between affordable prices and a sustainable pharmaceutical industry. 1st World Conference on Access to Medical Products and International Laws for Trade and Health in the Context of the 2030 Agenda for Sustainable Development', Taj Mahal Hotel, New Delhi, India.

#### 16 November 2017

'Global Drug Utilization Review: What's happening in Africa?' – EuroDURG Conference 2017, Technology & Innovation Centre University of Strathclyde, Glasgow, United Kingdom.

#### 12 September 2017

'The Evolving Health Legislation in South Africa in Terms of Access to Medicines', Copernicus Institute of Sustainable Development, Utrecht University, Section of Innovation Studies, The Netherlands.

#### 8 September 2017

'Affordable (Bio)therapeutics for Public Health', WHO Regional Office for Europe, UN City, Copenhagen, Denmark.

#### 6 September 2017

'Access to Quality and Affordable Medicines and (Bio)therapeutics, Including a South African Case Study' – Global Health & Tropical Medicine Course, University Medical Centre Utrecht, The Netherlands.

#### 10 - 14 July 2017

'FRPs and Equitable Access in a Global Context' – Pharmaceutical Policy Analysis Summer School 2017, Utrecht University, The Netherlands (as a panel discussant).

#### 10 - 14 July 2017

'An Introduction to the Essential Medicines' Concept: Balancing Innovation with Public Health Priorities'- Pharmaceutical Policy Analysis Summer School 2017, Utrecht University, The Netherlands (on behalf of N. Magrini).

#### 10 - 14 July 2017

'Global Pharmaceutical Pricing and Control Policies' – Pharmaceutical Policy Analysis Summer School 2017, Utrecht University, The Netherlands.

#### 10 - 14 July 2017

'Pricing and Reimbursement' – Pharmaceutical Policy Analysis Summer School 2017, Utrecht University, The Netherlands.

#### 10 - 14 July 2017

<sup>'20</sup> Years Since the South African National Drug Policy – What Has Been Achieved?' – Pharmaceutical Policy Analysis Summer School 2017, Utrecht University, The Netherlands.

#### 10 - 14 July 2017

'The 20 Years' Experience of the Essential Medicines Programme in South Africa'-Pharmaceutical Policy Analysis Summer School 2017', Utrecht University, The Netherlands (with Velisha Ann Perumal-Pillay).

#### 17 May 2017

'The 20 years' Experience of the Essential Medicines' Programme in South Africa' – Global Health Seminar, UMC Utrecht Julius Centre, Utrecht University, The Netherlands (with Velisha Ann Perumal-Pillay).



World Health Organization's Expert Committee on Selection and Use of Essential Medicines for 2017



Presentation at EURODURG 2017, in Glasgow



Colleagues at the Teaching Advancement at Tel Aviv University - poster presentation on e-Learning

Pharmaceutical Services Post – Apartheid in

South Africa' – Global Health Seminar, UMC

'Affordability and Equitable Access to Medicines

for Public health', inaugural address as holder

of the Prince Claus Chair in Development and Equity 2016-2018, Utrecht University,

'20 Years Since the South African National

Drug Policy – What Has Been Achieved?' –

International Seminar Programme, Drug

Innovation, UIPS Mini symposium, Utrecht

As chair holder Professor Suleman contributed

• 'The National Drug Policy – 20 Years and Still Going?', Gray A, Suleman F, Pharasi B, Padarath A, Barron P (eds). In South African Health Review 2017 (pp 49-58). Health Systems Trust, Durban (ISSN 1025-1715). 'Is there Price Transparency in the Pricing of

Medicines in the South African Private Sector?', Bangalee V, Suleman F. In South African

University, The Netherlands.

to two publications in South-Africa.

Medical Journal (in print).

Utrecht Julius Centre, Utrecht University,

'The Move towards Rationalizing

17 May 2017

The Netherlands.

16 May 2017

The Netherlands.

11 April 2017

PUBLICATIONS

.



Petra Brysiewicz, Suvira Ramlall, Mosa Moshabela and Fatima Suleman -Fellow PIs on NIH Grant at UKZN (DRILL) on Junior Faculty Development

#### POSTGRADUATE SUPERVISION

During her term as chair holder Professor Suleman is supervising the research of the following students.

- Dr Rianne van den Ham (postdoc)
- Ms Swathi lyengar (PhD candidate)
- Ms Moska Hellamand (undergraduate student)

#### **NWO-WOTRO**

NWO-WOTRO has generously supported the work of Professor Suleman by funding the position of her research assistant, Dr Rianne van den Ham. WOTRO supports scientific research on development issues, in particular poverty alleviation and sustainable development. Its scope includes all low and middle-income countries. WOTRO is a division within NWO (the Netherlands Organisation for Scientific Research). For its activities, WOTRO receives funding from the Dutch Ministry of Foreign Affairs.



INTERVIEW



1. PERSONNE Chef des trava Spécialis Assista

### 2.PERSONNEL PARAM 3.INFRAST

Bâtime •4 salles d'hospital •1 unité de phy •1 service des soins des urge

#### Appareillage

Appareil d'ar
 Lampes scia
 Bistouris éle
 Monite
 Amplificateur c
 Colonnes pour chirurg
 Kits pour urologie
 Dermatome à ai

#### 5.ORGANISATIC

-Consultations -Bloc op -Hospital Kiné-Phys

# FINDING A CURE FOR THE AILING SYSTEM OF BIO-THERAPEUTICS

THE GOOD NEWS: MEDICINES FOR THE TREATMENT OF SERIOUS DISEASES ARE AVAILABLE. THE BAD NEWS: FOR MANY PATIENTS THEY ARE UNAFFORDABLE. SCHOLARS SUCH AS **FATIMA SULEMAN** AND **BERT LEUFKENS** ARE ON A MISSION TO LOWER THE THRESHOLD.

Looking back, Professor Fatima Suleman thinks it was around the year 2000 when, for her, the whole thing got started. That is when she learned about the importance (and imperfect distribution) of essential medicines. It was the time, when HIV had become an issue in her home country of South Africa. Here was a new condition that could not be treated. The medicines to fight it did exist, but these medicines were too expensive for most people to afford them. It was that stark reality, that motivated her to look into medicines' policies in general and into medicine pricing in particular. It was what has brought her to the Netherlands too. We meet today in the David de Wied building of Utrecht University, which, together with the International Institute of Social Studies of Erasmus University Rotterdam, is a partner in the Prince Claus Chair. Utrecht University has appointed Suleman as holder of the chair from 2016 to 2018. In this position, she has been conducting research into the affordability of, and equitable access to, (bio)therapeutics for public health, in collaboration with scholars at Utrecht University and others. On this December morning, Suleman has come to the meeting room with one of these Utrecht

to the meeting room with one of these Utrecht scholars, Professor Bert Leufkens, a fellow thinker and a fellow warrior in the fight against inequity. Leufkens says that while here in Europe, medicines to treat HIV may be affordable, there are lots of other medicines which are not. And that "Europeans and South Africans see very similar issues in terms of negotiation power and the legal system. That is what brings Fatima and us together under the auspices of the Utrecht WHO Collaborating Centre for Pharmaceutical Policy and Regulation." Today, Suleman and Leufkens share their thoughts on the exorbitant prices of essential medicines and what it will take to bring these prices down.

#### History

Fatima Suleman: "Back in South Africa, I graduated from university around the time of the democratic elections, in the mid-nineties. I worked in a hospital where we had patients who slept underneath beds because there were so many patients and not enough beds. That was a hospital for the black African population. And then there were private sector hospitals, which were first world type of hospitals. The new Government of National Unity was facing pressure from pharmaceutical companies that were not South African based, who were very opposed to some of the policies that were being outlined by the government and even took them to court to fight decisions."

#### Change

Suleman: "I think there is still that subtle pressure that companies put on governments by saying that it will cost them so many jobs if the government introduces a certain policy or if they do not allow price hikes. In any part of the world, this is always going to be an issue. But I think that there is a lot more negotiating going on. There has not been a rush to go to



court. There has been a softer approach with the two sides trying to find common ground. Governments are starting to see they have power as well. They are the purchasers of the medicines. They have the budgets." Bert Leufkens: "Most societies have given the role of medicine development and marketing to pharmaceutical companies. On the other hand we have public health needs. The same goes for other sectors, such as transportation, housing, and food. But in particular with medicines, the perversities and power play are amplified. Medicine development is global, but at the end of the day there is an individual patient somewhere in the world who is in need of a certain medicine, which very often is unaffordable. That is my academic and my public policy interest. Can I understand what is happening? Can I help promote mechanisms for negotiations? In Europe, countries like the Baltic states and some southern European countries do not have access to European licensed medicines either."

#### Lessons

Suleman: "What we have learned in South Africa is that introducing any form of price control is not an easy thing to do. You need to be firm against the pressure from the medicine industry. But also you need to make the public understand what is happening. With HIV this was the case. Once civil society understood that companies blocked their access and charged high prices, a strong movement emerged. Companies saw they were receiving poor publicity and they knew they could not continue in that manner. We are now moving towards very expensive oncology medicines and hepatitis C medicines and we need to make the public understand why they are so unaffordable. Not just in low and middle-income countries, but in high income countries too.

"MEDICINES ARE UNAFFORDABLE IN LOW AND MIDDLE-INCOME COUNTRIES, BUT IN HIGH INCOME COUNTRIES TOO"

The second thing is to have a strong government that will say, affordable medicines are for the benefit of the population, but we do understand that companies have needs too. And then to be able to find a meeting point. If a company makes medicines that are too expensive, they are not going to have a market in which to sell them. But if they bring them into a price range that allows them to increase sales, it will mean that they will achieve a cost-effective production line." Leufkens: "This discussion fits very well in the rethink of the medicine development business "THERE IS LITTLE DISCUSSION ABOUT THE FACT THAT COMPANIES HAVE DEVELOPED GOOD MEDICINES" model. There is little discussion about the fact that companies have developed good medicines. The hepatitis C example is interesting. There, we have a group of medicines that are really efficacious and relatively safe, so there is no discussion about the benefits. However a question mark hangs above the sustainability of the pricing. There is a reward system that drives decisions to the perverse end. It is our job, as academics, to pinpoint these issues. To try to understand the mechanisms. Not just in terms of the costs, but also in terms of the motivations driving the companies."





#### Transparency

Suleman: "We often have no idea why medicines are priced in a certain way. What happens in some negotiations with governments is that companies say, we will have a list price that is higher than what I am offering you. This form of negotiation does little to increase transparency. Most governments have their population at heart, so they will agree." Leufkens: "The move towards greater transparency started with a discussion about prices. But increasingly, it also has a broader perspective. For a long time, companies did

### "TRANSPARENCY IS A KEY ISSUE TO ADDRESS"

not want to disclose what was happening in the clinical trials. Now, there is a strong push to be more transparent about those. But also governments and insurance companies were not very transparent. They, too, are being urged to explain why they make the decisions they are making. When we look at a more sustainable medicine development and affordability system, transparency is a key issue to address."

Suleman: "Everything needs to be clear. Who is paying for what, who is getting what? Some of the costs might be justifiable, but if that is the case, why hide it?"

#### Ethics

Suleman: "I understand that companies have shareholders to whom they must cater. But pricing something in such a manner that you can get a bigger return on investment is not ethical. Anyone who invests in the pharmaceutical industry needs to look at it as a contribution to the greater good rather than a kind of high-risk-high-gain kind of investment. I'm hoping the fact that people like Warren Buffet and Bill Gates are turning so much attention to it, will bring about change.

It is important that companies make clear where their research started. If it started within an academic institution and taxpayers' money was used in addition to the investment made by the pharmaceutical industry, then the government should have a say in how the price structure works."

Leufkens: "There is a challenge there. We are doing lifecycle analysis of high-quality medicines and we see that bits and pieces of the knowledge were developed at the academic hospital across the street from here, bits and pieces were developed in a laboratory there, parts of the clinical trial were done in Boston and Singapore and then there is a company in San Francisco which brings the medicines to the market. But the good thing is that we are having this global dialogue. There is, however, no linear correlation between transparency and trust. Often, the more people get to know about how the system works, the greater the chance they will start wondering what it is they are looking at. But if there is no transparency, there will be no trust at all."



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#### Initiatives

Suleman: "There are a lot of initiatives emerging of which pharmaceutical companies are wary. There is the Medicines' Patent Pool Initiative, through which companies in Egypt, Africa, and Russia are able to produce licensed hepatitis C medicines at a much cheaper price. Then there is the Neglected Disease Initiative which is looking at ways to get companies to share research initiatives, so that research and development can be done faster and cheaper. We have to be able to get research and development to the diseases that require medicines. If you look at new antibiotics, they are only prescribed as a last resort. Therefore, companies do not really see the economic need to produce them. Governments have to be able to say, this is a public health imperative and we need those medicines. The current model is based on economic drivers, not on what the world needs."

Leufkens: "We also need to look at what governments can add in terms of smarter regulations. Of course companies need to



show whether a medicine is efficacious and safe. But there is a lot of bureaucracy and there are many unnecessary tests. There is a strong regulatory science component that is investigating a reshape of the regulatory system, so that the argument of companies that they have to carry out all these tests will no longer be valid. Given the increasing need for high-quality medicines worldwide, governments should think about how they can contribute to a solution."

#### Monitoring

Suleman: "Governments have been employing pricing policies for a number of years now, but academics have been slow to figure out ways to measure the effect they have had. But now we do have the means to measure policy implementation. It is too late to go back and see what the changes are because the data might not be there anymore. But to those implementing policies now, we say, please do these types of studies to see whether the policy is effective or not, so that other countries can learn from them."

#### **Prince Claus Chair**

Suleman: "When I accepted this position, I don't think I realised all the things that would happen to me during my time as chair holder. It has brought a lot of invitations to discuss this issue with policy makers and government officials around the world. I am also speaking to young people who are concerned about the issue. Another benefit is that many people who have been working alone are starting to meet with me and want to work together. That is important for sustainability and it represents an effect that will go beyond my time at the Prince Claus Chair."

"MY COLLEAGUES CALL ME MS GLASS HALF-FULL"

Leufkens: "To add to that, what I appreciate is that Fatima has brought a greater variety of people to the scene. We now not only have academics participating, but also civil servants, activists, and industry representatives having a constructive dialogue. When it comes to capacity building, it is not only about knowledge and data etcetera. It is also about a positive attitude to the problem. This attitude might just be the key." Suleman: "My colleagues call me Ms Glass Halffull. I think you have to be optimistic. It can be quite a struggle sometimes, but even if at this point in time we are only able to highlight the issue and create more activism around it, it will be worth it." CHAIR HOLDER

2015-2017

## PROFESSOR SARADINDU BHADURI

"My tenure as holder of the Prince Claus Chair has been one of the most cherished episodes in my academic career so far. The Chair has helped me reach out to an immensely diverse group of researchers and the excellent academic environment in the Netherlands. It has helped me connect to scholars with varied disciplinary backgrounds and with an array of different methodological approaches to innovation and development research. At the same time, the Chair has helped me obtain a better international standing for my research on grassroots innovations and bottom-up frugal innovation. I have particularly benefited from the inter-disciplinary research approach of my colleagues on frugal innovations at the Centre for Frugal Innovation in Africa (CFIA), a collaboration between the universities of Leiden, Delft, and Rotterdam. Their collegiality has been par excellence.

A highlight of the tenure was certainly the inaugural address I delivered on 23 May, 2016 on 'Frugal Innovations by 'the Small and the Marginal': an Alternative Discourse on Innovation and Development' at the Kloosterkerk in The Hague. The event was really special to me because of the presence of the former Indian ambassador in the Netherlands, His Excellency Mr J.S. Mukul. With her gracious presence, Her Majesty Queen Máxima, the Patron of the Chair, made the event most memorable. The experience of sharing my research with the noted academicians of all the leading universities in the Netherlands, and the activists of the various international development organisations made the event an experience I shall cherish for the rest of my life.

The Chair enabled me to develop a research base in Africa, with field visits, conferences and research collaborations. This is a meaningful addition to my research profile, as no research on frugal, grassroots informal sector innovations can be complete without an understanding of the African context. Dr Kinsuk Mani Sinha, the Prince Claus Chair postdoctoral fellow, ably assisted me in my research projects during the tenure. We are both looking forward to giving our project on frugal innovations in the lock and security sector in India and Kenya its final shape in the coming months.

The leading Dutch newspaper 'Het Financieele Dagblad' covered our research last year. This coverage was then followed up by an invitation by the Dutch Ministry of Foreign Affairs to give a lecture on 'Frugal Innovation in Development Policy: a Conjectural Roadmap'. This year, we had occasion to share our research with UNESCO's 'VIA Water' project, too. These events flag the traction our research has received with policy makers and practitioners of development.

In India, I was invited to be Convenor of the 4th 'INDIALICS Conference and Training Programme' (the Indian chapter of the Global Network of Economics of Learning, Innovation and Competence Building), which took place in New Delhi in November 2017. This is the largest network on innovation studies in India, and the conference has given me an opportunity to link the CFIA with a diverse group of researchers on frugal and grassroots innovation from India and Africa. With my colleagues at the CFIA, I am taking concrete steps to convert this network into a multicountry collaborative research programme on frugal innovation.

The Curatorium of the Prince Claus Chair has provided all necessary support in ensuring a smooth functioning of the Chair. The scholarly networks developed during my tenure have translated into exciting plans for several academic collaborations in the coming years. This, I believe, will help realise the goal of the Chair to promote lasting international collaborations in the ever-evolving field of development and equity."



CHAIR HOLDER

2017-2019

## PROFESSOR ALI BILGIÇ

On the recommendation of the Curatorium of the Prince Claus Chair, the International Institute of Social Studies (ISS)/Erasmus University of Rotterdam has appointed Dr Ali Bilgiç as holder of the Prince Claus Chair of Development and Equity 2017-2019.

Professor Bilgiç is from Turkey. Presently, he is a lecturer in politics and international relations at Loughborough University in the UK. His research areas include critical security studies, migration, European Union foreign policy, and external relations as well as Middle East and North African politics.

His thematic focus as chair holder will be on the human security approach to migration. Professor Bilgiç's research is designed to help us understand migration more comprehensively as a social, political and economic process and to identify and respond to associated policy challenges and dilemmas.

Dr Bilgiç has held the Prince Claus Chair since the 1st of September 2017. He will spend part of his two-year appointment at the ISS in The Hague. He will work closely together with other academics of ISS and other faculties of Erasmus University as well as with researchers from other universities in the Netherlands working in the area of migration, mobility and human security.



## PREVIOUS HOLDERS OF



#### 2014-2016

Chilean Professor Javier Couso was appointed to the Prince Claus Chair by Utrecht University. A specialist in the field of sociology of law and comparative constitutional law, Professor Couso conducted a study on the institutional and socio-political determinants of judicial independence in new democracies, with a focus on Latin American countries.

#### 2013-2015



Professor Olajumoke Oduwole, from Nigeria, was appointed to the Prince Claus Chair by the International Institute of Social Studies of Erasmus University. During her tenure she focused on the nexus between international law and the implementation of the Right to Development (RTD). She looked at the practical effectiveness of the RTD in relation to development in Africa.

#### 2012-2014



Professor Aylin Küntay, from Turkey, was appointed to the Prince Claus Chair by Utrecht University because of her work in the field of language and the socio-cognitive development of young children. Professor Küntay's research enables children with less-well-off parents to improve their social status by helping them to improve their language proficiency.

#### 2011-2013 Professor Stella Qui



#### 2010-2012





#### 2009-2011



Professor Patricia Almeida Ashley was appointed to the Prince Claus Chair by the International Institute of Social Studies. The Brazilian professor is known for her interdisciplinary approach to Socially Responsible Entrepreneurship (SRE) and her research on the relationship between SRE and important social issues.



#### 2008-2010

Professor Irene Agyepong, from Ghana, was appointed to the Prince Claus Chair by Utrecht University. As a public health expert, Professor Agyepong is a strong advocate of investing simultaneously in research into public health and the development of health policy. In her research she has been concentrating on how to manage and transform health systems in Sub-Saharan Africa.

#### 2007-2008



Professor Alcinda Honwana was appointed to the Prince Claus Chair by the International Institute of Social Studies. Born in Mozambique, Professor Honwana is an authority on child soldiers in Africa and on the predicament of young Africans in the context of ongoing globalisation processes in postcolonial Africa.

#### 2006-2007



Professor Nasira Jabeen was appointed to the Prince Claus Chair by Utrecht University. Coming from a Pakistani background, Professor Jabeen focuses her teaching and research on the possibilities and constraints of good governance as a concept in the developing world.

#### 2005-2006 Professor Rema Ha



Professor Rema Hammami was appointed to the Prince Claus Chair by the International Institute of Social Studies because of her impressive academic contribution, as an intellectual champion, to peace and co-existence in the Palestinian Territories. Her gendered approach provides a valuable point of entry into issues of governance, civil society, citizenship, rights and peace.







2004-2005

Professor Gaspar Rivera-Salgado was appointed to the Prince Claus Chair by Utrecht University. The Mexican professor was appointed on the basis of his academic work in the field of indigenous rights, particularly in Latin America and the United States.

#### 2003-2004

Professor Amina Mama was appointed to the Prince Claus Chair by the International Institute of Social Studies. The Nigerian professor Mama was appointed for her contribution to the academic field of African culture and its relationship to development.

#### 2002-2003

Professor S. Mansoob Murshed was appointed as the first holder of the Prince Claus Chair by Utrecht University. Professor Murshed is an economist from Bangladesh and was appointed for his academic work in the fields of trade and freedom of trade and in the field of peace and conflict management in relation to economic development.

#### CURATORIUM

The Curatorium is responsible for appointing new Prince Claus chair holders. Her Majesty Queen Máxima of the Netherlands is the Patron of the Prince Claus Chair. In 2017, the Curatorium comprised the following members:

- Professor Louise J. Gunning-Schepers
  Chair
- Professor Ton Dietz
  Vice Chair
  Director of the African Studies Centre (until August 31, 2017)
   and Co-chair LeidenASA
- Professor Bert van der Zwaan
  Member
  Vice Chancellor of Utrecht University
- Professor Inge Hutter Member Rector of the International Institute of Social Studies/Erasmus University Rotterdam

Linda Johnson, BA (Hons), MBA, is Secretary to the Curatorium



Inge Hutter, Ton Dietz, Louise J.Gunning-Schepers, Bert van der Zwaan, Linda Johnson

# PARTICIPATING

The International Institute of Social Studies (ISS) in The Hague is part of Erasmus University Rotterdam (EUR). It is a graduate institute of policy-oriented critical social science, founded in 1952, and hence able to draw on 65 years of experience.

ISS is a highly diverse international community of scholars and students from the global south and the global north, which brings together people, ideas and insights in a multidisciplinary setting. This environment nurtures, fosters and promotes critical thinking, and ISS researchers conduct innovative work on fundamental social problems. ISS offers a PhD programme, a Master's programme and various short courses. Between 300 and 400 students from more than 50 different countries study at ISS each year. The PhD community numbers over 130 researchers.

Key to the ISS philosophy and practice is the wish to make a contribution to achieving social justice and equity at a global level. ISS has strong partnerships with organisations and individuals all over the world, including its 13,000+ alumni. These partnerships make up a network in which the co-creation of knowledge and an integrated approach to research and teaching can flourish and generate social impact. ISS research focuses on global development and social justice based on current global issues. The main research themes are: civic innovation, development economics, governance, law and social justice, political ecology.

ISS shares expertise with a wider public by providing high-level policy advice and serving as a platform for debate and the exchange of ideas.

Further information about ISS can be found at www.iss.nl

International Institute of Social Studies



Utrecht University is one of Europe's leading research universities, recognised internationally for its high quality, innovative approach to both research and teaching.

Founded in 1636, the university has always focused strongly on research. Owing to its solid grounding in discipline-based scholarship, Utrecht University is at the forefront of developments in interdisciplinary knowledge. The university has chosen four strategic research themes: Pathways to Sustainability, Institutions for Open Societies, Life Sciences and Dynamics of Youth.

Utrecht University participates in several international networks, including the League of European Research Universities (LERU), the International Association of Universities (IAU) and the McDonnell International Scholars' Academy. Utrecht University, the University of Toronto and the University of Hong Kong (China) have joined forces to find ways of improving health in urban areas. Utrecht University is home to 31,000 students and 6,800 staff members. Each year, more than 2,000 students and researchers come to the university from abroad. Commitment, inspiration, ambition and independence are Utrecht University's core values. The university works collaboratively with the business sector to undertake societally relevant and innovative research.

More information can be found at www.uu.nl



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His Royal Highness Prince Claus of The Netherlands, in his acceptance speech upon receiving an honorary fellowship at the International Institute of Social Studies,1988:

## PROPOSITION #8

"IN DEVELOPMENT COOPERATION, AS IN MANY OTHER FIELDS, OUTPUT IS MORE IMPORTANT THAN INPUT. WE ARE STILL FAR TOO FIXATED ON INPUT. SUSTAINABILITY IN SOCIOLOGICAL, ECONOMIC AND ECOLOGICAL TERMS SHOULD BE THE PARAMOUNT CRITERION OF SUCCESS."

