

*Joyce Fertility Support Centre Uganda, Building
an empowered community of citizens*

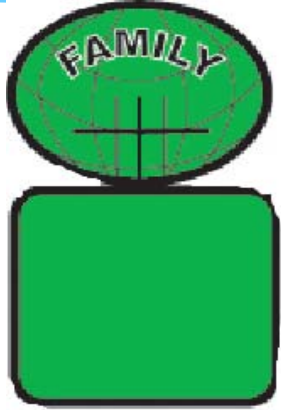
9th International iCSi Conference: Budapest 2008



Developing Countries & Infertility: The Role of Patients

PRESENTER

**Mrs. Rita Sembuya,
Executive Director,
Joyce Fertility Support
Centre Uganda (JFSCU)**



Infertility – The Views

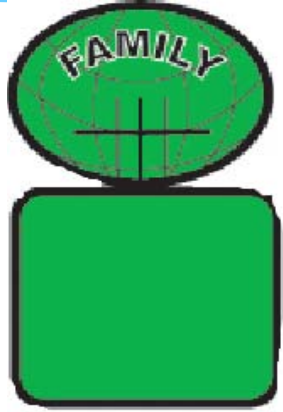
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The problem of infertility has existed long enough in the presence of the human race.

Biblical allusions; Abraham and Sarah (the couple) did not have Children until their advanced age. (1)

Jacob and Rachel could not have children, and there arose a state of vulnerability, “Give me children or else I die”, Rachel tells her husband Jacob. (2)

African Traditional Society holds child birth as a completion of life. In the same society, “a marriage is complete only after the birth of the first child”. (3)

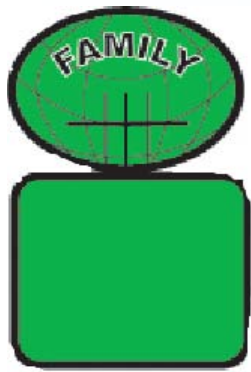


Global conventions and the case of infertility:

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United Nations Declarations on Human Rights; “Men and Women of full age without any limitation due to race, nationality or religion have a right to marry and found a family.” (4)

European Convention on Human Rights guarantees respect for family life and the right to found a family.(5)



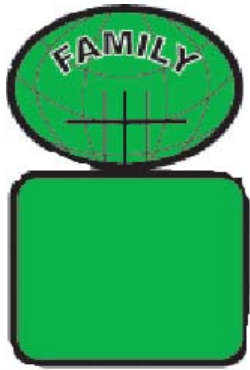
Roles of Non Profit Organizations

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World Health Organization (WHO), produced a report in 2001 on medical, social and ethical aspects of Assisted Reproduction

In it's forward, the report reveals that infertility affects more than 80 Million people worldwide. Most of those who suffer from infertility live in the developing countries.(6)

2002, World Health Organization (WHO) convened a meeting to support infertility management within the family planning program. In this meeting, experts participated in a priority ranking where infertility scored higher from its position of being in the lowest priority status of the World Health Organization (WHO). (7)



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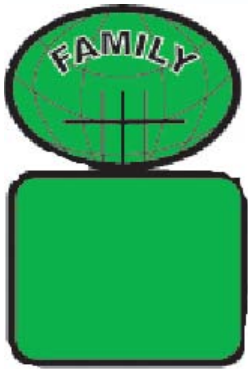
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1980 to present, there has emerged Patient Organizations, a critical mass of advocates inserting their voices to the plight of patients' perspectives and requiring roles as partners in service delivery.

1999 - iCSi – International Consumer Support for Infertility; Is a global patient leaders' community; empowering patients to become full partners in ART healthcare.

iCSi is spread in all the world regions; Africa, Asia Pacific, Europe and Americas with about 40 patients' organizations worldwide.

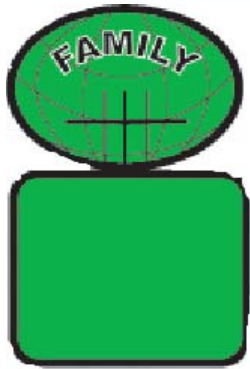
National and International perspectives from patient organizations have highlighted the lack of accessibility, affordability and quality care for infertility treatment.



International voices

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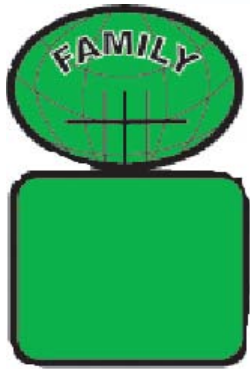
- Rita Sembuya – Joyce Fertility Support Centre Uganda
“Infertility unaddressed and difficult problem in the whole of African”.
(iCSi symposium Berlin 2004.)
- Dr. Yukari Semba: Friends of Finrrage Network for infertile women in Japan, *Infertility treatment and population policy in Japan.*
(iCSi symposium Berlin 2004).
- Sandra K. Dill – iCSi *“International Treatment Difference. Policy, Politics, Partnerships and ART.”*
- Evelyn Madziba – The Fertility Network Zimbabwe.
“Infertility: A patient’s perspective” (Harare on the 25th of May 2007).
- Pamela Madsen - American Fertility Association
(A global fertility survey on *“Knowledge base on fertility”* 2006)
- Beverly Hanck – Infertility Awareness Association of Canada, conducted a survey. *“Infertility Treatment – The Patient’s Perspective.”* (8)



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Advocates with significant impact: Developing Regions

- **Israel:** Total funding of infertility until the couple have two children the campaign was worn by the patients.
- **Uganda:** The start of Assisted Reproductive Technology was initiated by patients organization.
- **Zimbabwe:** Infertility awareness was started by patient organization.
- **Kenya:** The starting of the task force to survey the prevalence of infertility is an initiative of patients.(9)
- **Argentina:** The law for provision of treatment of babies born out of ART was initiated by patients.



Advocates and leaders of patients' organizations - developing regions

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**Mrs. Ofra Balaban K.
Chen Patient Fertility Assn
Israel**



**Mrs. Rita Sembuya
Joyce Fertility Support
Centre Uganda**



**Mrs. Evelyn Madziba
The Fertility Network Zimbabwe**



**Mrs. Sarah Ndwiga
Hope Fertility Support Centre
Kenya**



Maria Isabel de Rolando
Concebir Argentina



Athen Pedro
Women's Infertility Support
Programme South Africa

**No more
Need to
whisper**



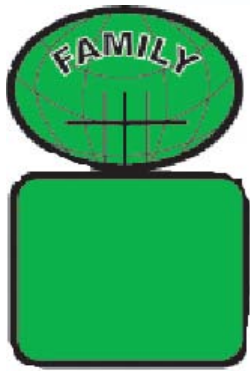
Mrs. Fummi Kofo Alokun
Option Infertility Support
Organization Nigeria



Ms. Estela Chardon
Concebir Argentina



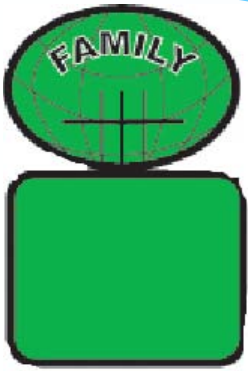
Mrs. Betty Chishava
Chipo Chedu Trust
Zimbabwe



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The enabling environment for infertility management calls for:-

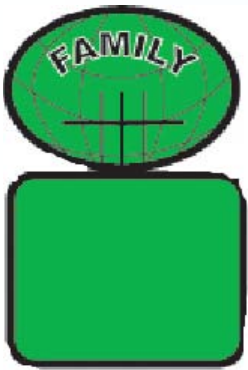
- Political will of the countries
- Documentation of prevalence using demographics
- Participation of local health and social scientists in countries
- Examining the levels of technology in infertility treatment of existing practitioners
- Adaptability of community; cultures, religions of the countries including traditional healers.
- Consideration of other factors that form the disease burden; cancer, HIV/AIDs, STDs and other anomalies; *fibroids, cysts ...*



Patients' roles

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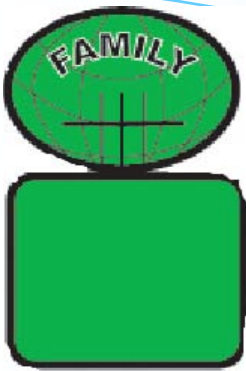
- Implementing guidelines and laws regarding infertility treatment
- Patients projecting their voices in all discussions
- Educated patients in organized institutions
- Coordination of networks: *governments, health providers, media and civil societies*
- Fighting stigma
- Replicating best practices and creating a critical mass



Observations

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- Despite the conventions and declarations, infertility for developing countries remain a neglected disease.
- World Health Organization (WHO) report, though very informative and well researched, has not provided a starting point for the management of infertility in developing countries.
- The meeting of family planning including infertility strategic plan was not further discussed or followed, yet its implementation and phase are about to expire 2004 – 2009. (11)
- Infertility treatment in developing countries is most needed, but the strategic planning of its implementation must answer for the barriers that have kept the region behind the rest of the world for so long.

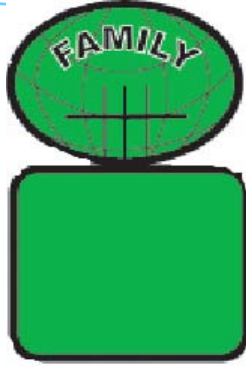


What are these Barriers?

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- Community attitudes and culture
- Question of silence by those suffering from infertility
- Health systems based on top-down criteria
- Brain drain of human resources from developing to developed countries
- Country budget determined by other economies
- Difficulty in managing sustainability of projects
- No initiatives to creating local resources, entrepreneurship start-up conditions
- Demographic records not in place

In order for infertility treatment to succeed, the community must invent, replicate and sustain operations.



In Pictorial

Prof. Willem Ombet in Uganda to see work done in infertility treatment and awareness

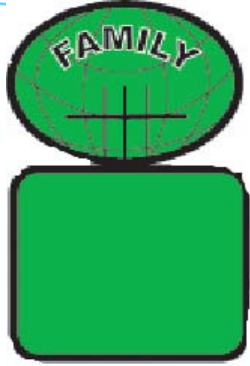
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Prof. Willem Ombet with Doctors, Member of Parliament, Joyce Fertility Staff and members



Prof. Willem Ombet, Joyce Fertility staff and member at Kampala Gynecology & Fertility Centre – IVF Centre





Pictorial cont'd..

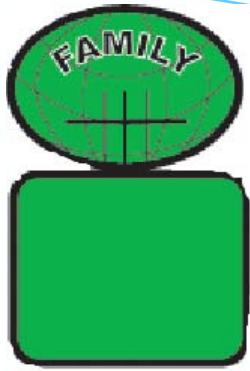
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*Prof. Willem Ombelet in the faculty of medicine of
Makerere University with Prof. Luboga, Dr. Kuteesa,
Rita & Rose of Joyce Fertility.*



*Meeting organised by Joyce Fertility on the presentation
of infertility treatment with Prof. Willem Ombelet*

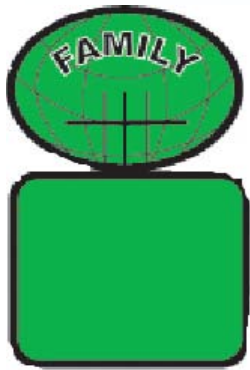




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Acknowledgment

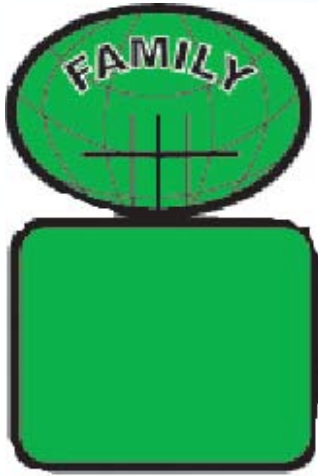
- Joyce Fertility Support Centre Uganda team
- Prof. Dr. Willem Ombet - Genk University Belgium
- International Patient Leaders' Community
- International Speakers – Patient Advocates
- World Health Organization
- Sponsors of the meeting for enabling environment to speak



References

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- (1) Genesis Chapter 21*
- (2) Genesis 30:1*
- (3) African Traditional Society*
- (4) Universal Declaration of Human Rights, Article 16.1, United Nations 1948*
- (5) Articles 8 and 12*
- (6) Ref. (Current Practices and Controversies in Assisted Reproduction).*
- (7) WHO – Family Planning including Infertility Strategies 2004 – 2009*
- (8) Arusha expert meeting presentation, “Patients’ Voice”*
- (9) African region, iCSi website*
- (10) Walking egg, Prof. Willem Ombelet”*
- (11) WHO Report 2002*



Joyce Fertility Support Centre Uganda Building an empowered community of citizens who understand their health rights and are able to partner with providers and stakeholders within the health system. Our priority attention is infertility.

THANK YOU FOR YOUR ATTENTION