



International Retinitis Pigmentosa Association
7th World Congress – Johannesburg South Africa
13th – 16th November 1992
Hosted by: RP Foundation of South Africa

**FIGHTING
BLINDNESS**

Breaking New Frontiers

[37]

RP Foundation of S.A.
P.O. Box 2395
Primrose 1416
Tel: (011) 825-1132/3
Fax: (011) 825-6662

Mr Z. De Beer
Chairman - CODESA
P O Box 307
Isando 1600

18th February 1992

Congress Scientific Committee

Prof. N. Welsh
Prof. J. Marshall (UK)
Dr. J. Felix (USA)
Prof. J. Hollyfield (USA)
Prof. P. Beighton
Prof. T. Jenkins
Prof. A. Murray

Dear Mr De Beer,

As Chairman of the Retinitis Pigmentosa Foundation of South Africa, and Vice-President of the International Retinitis Pigmentosa Association [IRPA], I would formally like to invite you to be our Guest of Honour at the Gala Banquet of the 7th World Congress of IRPA, which will be held in Johannesburg on Saturday 14th November 1992.

Congress Committee

Mr G. Cousins (Chairman)
Mr S. Matus (Organiser)
Mr R. Bristol
Mrs L. Bristol
Mr A. Cousins
Mr F. De Sousa
Mr J. Foster-Greenwood
Ms H. Firer
Mr J. Hurwitz
Mrs C. Medefindt
Mr D. Ogilvie

The RP Foundation of S.A. is a full member of IRPA and has been granted the right to host the next RP World Congress in Johannesburg. This will be the first time in the 22 year history of the movement that the Congress will be held on the African continent. The RP Foundation of S.A. is currently the only African member of IRPA.

Trustees

Mr J. Bennett
Mr D. Carlisle
Gen. A. Fraser
Mr R. Williams

In keeping with the historical significance of this Congress for RP, and in view of our intention to make a significant contribution to the world-wide efforts to find a cure for inherited retinal degenerative diseases, we would be extremely grateful if you would honour us with your presence at the Banquet. This would also be in line with the practice at previous congresses where the banquets have been attended by the Governor General in Australia and the President in Ireland.

Honorary President

Mr B. Fordyce

Hoping you are able to accept our invitation,
Yours sincerely,


GORDON COUSINS
National Chairman - International Vice-President



F.R. 088002270001

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HONORARY PRESIDENT
Mr. B. Fordyce

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Mr. D. Carlisle
Gen. A. Fraser
Mr. R. Williams

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Prof. G. Gericke
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Prof. H. Meyer
Prof. A. Murray
Prof. A. Peters
Prof. R. Stegman
Dr. R. Stewart
Prof. A. Stulting
Prof. M. van Rooyen
Prof. N. Welsh

RP Foundation of South Africa RP Stigting van Suid – Africa

RP FOUNDATION OF SOUTH AFRICA FACT SHEET

- 1979 First Steering Committee meeting held in Cape Town.
- 1980 Transvaal Branch formed in Johannesburg. Mr G. F. Cousins elected Chairman.
- 1980 Constitution adopted in Cape Town.
- 1980 National association established.
- 1981 First research project on RP by Wits Technikon.
- 1982 Natal Branch established.
- 1983 Change of name from South African Retinitis Pigmentosa Society to RP Foundation of S.A.
- 1985 S.A. Scientific Advisory Board established.
- 1990 Board of Trustees established.
- 1990 Outreach Programme established.
- 1990 First major grant to U.C.T. for Genetic research.
- 1990 S.A. awarded 1992 IRPA Congress.
- 1991 Ph.D Studentship programme launched.
- 1991 Northern Transvaal Branch established.



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RP FOUNDATION OF SOUTH AFRICA **FACT SHEET**

RP is the name given to a group of eye conditions that cause deterioration of the cells of the retina and lead to loss of vision and generally, to total blindness. The most common forms are:

RETINITIS PIGMENTOSA,
USHERS SYNDROME,
MACULAR DEGENERATION.

OCCURENCE

Researchers estimate that one in 3,000 in the population are sufferers of RP, and one in 2,000 suffer from some form of Retinal Degeneration. Based on these statistics, there are a probable 15,000 sufferers in South Africa and 3,000,000 world wide.

FORMS OF INHERITANCE

RP is inherited in 3 modes: Dominant, X-Linked, and Recessive. One in eighty in the population are probable carriers of the recessive gene, the most common form of RP. Ushers Syndrome is the most common form of deaf-blindness and is recessively inherited. Macular Degeneration is the major cause of vision loss in the elderly.

RESEARCH

Worldwide research in the fields of Molecular Genetics, Biochemistry, Cell Biology, Immunology, Morphology, Electrophysiology, Animal Models and Clinical Studies have resulted in major breakthroughs in the understanding of Retinal Degeneration. Encouraging results in the field of Molecular Genetics have resulted in the isolation of 8 RP genes. The Genetics Dept. of U.C.T. is currently screening local families to track the genes involved. Molecular Genetics probably holds the greatest promise for a cure.



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RP IRPA FACT SHEET

IRPA MEMBER COUNTIES : U.S.A., AUSTRALIA, U.K., CANADA,
FINLAND, FRANCE, GERMANY,
HOLLAND, IRELAND, PAKISTAN,
SOUTH AFRICA, SWITZERLAND.

OBSERVER STATUS : AUSTRIA, BELGIUM, DENMARK,
SWEDEN, NEW ZEALAND, ITALY,
MEXICO, PERU.

ASSOCIATIONS : COSTA RICA, PANAMA, SPAIN,
INDIA, GREECE.

- 1971 National RP Foundation established in Baltimore, USA.
1973 Scientific Advisory Board established.
First International Scientific Workshop held in USA.
1974 First Multi-Disciplinary Research Centre established at
Harvard Medical School, Boston, USA.
1978 First Congress of IRPA held in U.K.
1981 Second Congress of IRPA held in Baltimore, USA.
1982 \$1000,000 is committed to RP research by American
Foundation.
1984 Third Congress of IRPA held in Helsinki, Finland.
1986 Fourth Congress of IRPA held in Germany.
1988 Fifth Congress of IRPA held in Melbourne, Australia.
1990 Sixth Congress of IRPA held in Dublin, Ireland.



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CHARTER

OUR AIMS

The Retinitis Pigmentosa Foundation is dedicated to finding the cause of, and treatment for inherited, retinal degenerative diseases. While aggressively promoting research to resolve the problem, we also aim to do as much as possible to assist sufferers in coping with their condition.

OUR PHILOSOPHY

We believe that we need to be actively involved in influencing the research community to focus on RP. We also need to be actively involved in fund raising and self-help activities. We cannot sit back and expect help from the Government or the community, without our active involvement.

OUR MEMBERSHIP

Membership of the Retinitis Pigmentosa Foundation is open to all sufferers of RP, their friends and their families, irrespective of age, race, colour or creed. Our members become actively involved in the administration of the RP Foundation, and our National Management Committee is comprised largely of sufferers and their families.

OUR POLICY

We believe in growing the Foundation by the establishment of independent, self-supporting branches, who affiliate and contribute to the national organisation by choice. We have a professional approach to all of our activities and the standards we set in our advertising, literature and administration are of the highest possible.

OUR COMMITMENT

Finally, we are committed to eventually dissolving our Foundation, having found a successful treatment and cure for Retinitis Pigmentosa and other allied, retinal degenerative diseases.



MANAGEMENT COMMITTEE\CORRESPONDENCE\ACKNOWLEDGEMENT

Mr G Cousins
National Chairman - International Vice-President
P O Box 2395
PRIMROSE
1416

Dear Mr Cousins

We hereby acknowledge receipt of your letter dated 18 February 1992.

Your invitation will be forwarded to Dr De Beer for his attention.

Yours sincerely

Murphy Morobe
Head: CODESA Administration

CONVENTION FOR A DEMOCRATIC SOUTH AFRICA

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