

Fundraising
Information
For Rare Diseases
SA

LIVING
BEYOND
RARE
DISEASES

Who is Rare Diseases South Africa?



Who is Rare Diseases south Africa

Rare Diseases South Africa is a leading patient organization within South Africa, working towards improved quality of life for all those impacted by rare diseases.

Our MISSION

Advocate and facilitate engagement between those with the ability to prevent, intervene, treat and provide supportive care for those impacted by rare diseases.

How do we use our funding?



- **Patient navigation:** Ensuring a challenge-free, supported journey from presentation of symptoms to end-of-life, for patients affected by rare diseases.
- **Advocacy and expanding access:** Representing patients affected by rare diseases with regards to policy, healthcare services and delivery.
- **Community Engagement:** Collaboration with civil society to ensure greater awareness and networking platforms for rare diseases in South Africa.

Our IMPACT in Numbers



1205 Registered Patients
224 Support Groups
1404 Healthcare Professionals
613 Different diseases
469 Rare ACTivists

NPO Information



Non Profit Company Registration Number:
2016/071131/08

Non-Profit Organization Registration Number:
120-991

Public Benefit Organization Number:
949 305 0182

B-BBEEE Recognition:
100%

How can you DONATE?



Banking Details:

Rare Diseases South Africa

FNB – Sunninghill,

Branch Code: 251655

Acc No: 624 11658 034

Ref: your email address

Online

www.rarediseases.co.za/donate

Monthly Debit Order

<https://www.rarediseases.co.za/debitorder>

Contact Us



hello@rarediseases.co.za



rare diseases south africa



+27 10 594 3844



@rarediseasesa

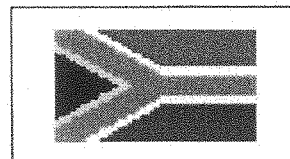


+27 72 476 7552



rarediseasesa

www.rarediseases.co.za



CERTIFICATE OF REGISTRATION OF NONPROFIT ORGANIZATION

In terms of the Nonprofit Organisation Act, 1997, I am satisfied that

Rare Disease Society of South Africa

(name of the organisation)

meets the requirements for registration.

The organisation's name was entered into the register on **14 May 2013**
(date)

Registration number **120-991 NPO**

Director's signature

[Handwritten signature]

Department of Social



Development

COMMISSIONER OF OATHS

Gert Oosthuizen

CA(SA)

Saica Number: 05154321

10 Mt Sherman

Midlands Estate

MIDRAND

[Handwritten signature] 2015/09/03

TRUE COPY

**Certificate issued by the Commissioner of Companies & Intellectual
Property Commission on Wednesday, March 9, 2016 at 15:17**



COR14.3: Registration Certificate

Registration Number: 2016 / 071131 / 08
Enterprise Name: RARE DISEASES SOUTH AFRICA

ENTERPRISE INFORMATION

Registration Number 2016 / 071131 / 08
Enterprise Name RARE DISEASES SOUTH AFRICA NPC
Registration Date 01/03/2016
Business Start Date 01/03/2016
Enterprise Type Non Profit Company
Enterprise Status In Business
Financial Year End February
TAX Number 9493050182

Addresses	<u>POSTAL ADDRESS</u>	<u>ADDRESS OF REGISTERED OFFICE</u>
	SUITE 135 PRIVATE BAG X43 SUNNINGHILL GAUTENG 2157	10 MIRWANI ROAD SUNNINGHILL SUNNINGHILL GAUTENG 2157

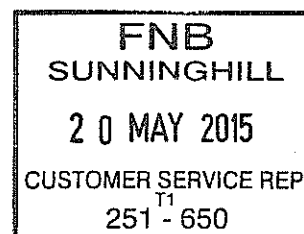
ACTIVE MEMBERS / DIRECTORS

Surname and First Names	Type	ID Number / Date of Birth	Appoint. Date	Address
DU PLESSIS, KELLY VICTORIA	Director	8502250094080	01/03/2016	Postal: SUITE 135, PRIVATE BAG X43, SUNNINGHILL, GAUTENG, 2157 Residential: 10 MIRWANI ROAD, SUNNINGHILL, SUNNINGHILL, GAUTENG, 2157
MC CREEDY, SHEVAUN TALIA	Director	8310150040082	01/03/2016	Postal: PO BOX 35720, NORTHCLIFF, NORTHCLIFF, GAUTENG, 2115 Residential: UNIT 7 LAKESIDE VILLAGE BLUEBERRY R, EAGLE CANYON GOLF ESTATE, HONEYDEW, GAUTENG, 2170
STERGIOPOULOS, NICOLA HELEN	Director	9009190046088	01/03/2016	Postal: PO BOX 71391, BRYANSTON, BRYANSTON, GAUTENG, 2021 Residential: 97 MONTE FALCO, SUNSET BOULEVARD, FOURWAYS, GAUTENG, 2191



Account Confirmation Letter

Date: 20/05/2015



To whom it may concern

ACCOUNT CONFIRMATION

We hereby confirm that RARE DISEASE SOCIETY OF SOUTH AFRICA (REG 120-991 NPO)
(name of entity/customer) holds the following account/s with FNB:

Account type	Account number	Branch	Branch code	Date opened
CHEQUE	62411658034	SUNNINGHILL	251-650	14/05/2013

We confirm that the following persons have been appointed as authorised representatives to act on behalf of the client:

1. MRS KELLY V DU PLESSSIS (ID 8502250094080)

The information provided in this letter is a true reflection of the records that were available to us as at the date of this letter. The bank shall not be held responsible for any subsequent changes in information contained in this letter.

Yours faithfully



N BASI



PREMIER VERIFICATION

B-BBEE Beneficiary Recognition Certificate
Issued to:

Rare Diseases South Africa

Unit 33 Waterford Office Park, Waterford Drive, Fourways, Johannesburg, 2191

PBO Number: 930044787

NPO Number: 120-991-NPO

Charity Sector	Health and Disease
Black Beneficiary Base	84.00%
B-BBEE SED Recognition	100.00%
SANAS Number:	BVA100
Issue Date	09 April 2018
Expiry Date	08 April 2019
Certificate Number	PVC_180401

Matthew Kearns
Premier Verification (Pty) Ltd

Office
Head Office

Enquiries
Mr W Molotsi

Telephone
(012) 483 1534

Facsimile
010 208 3301

PBO Reference No.
930060119

Income Tax Reference No.
9493050182

Date
13 February 2018

The Representative
Rare Diseases South Africa NPC
P O Box 114
Fourways North
2086

South African Revenue Service

271 Veale Street
Brooklyn, Pretoria
PO Box 11955, Hatfield, 0028
Tel: +27 (12) 483-1700
www.sars.gov.za
teu@sars.gov.za

Dear Sir

APPLICATION FOR INCOME TAX EXEMPTION APPROVED: RARE DISEASES SOUTH AFRICA NPC; PBO 930060119

The South African Revenue Service (SARS) would like to confirm that your application for exemption from income tax has been approved as you meet the requirements of a Public Benefit Organisation (PBO) set out in section 30(3) of the Income Tax Act No 58 of 1962 (the Act). Your Income Tax Exemption has been granted in terms of section 10(1)(cN) of the Act with effect from 05 February 2018. Annual receipts and accruals will therefore be subject to the provisions of section 10(1)(cN) of the Act and accruals and receipts from trading or business activities which fall outside the parameters of section 10(1)(cN) will be subject to tax.

The following exemptions also apply and are limited to:

1. The public benefit organisation has been approved for purposes of section 18A(1)(a) of the Act and donations to the organisation will be tax deductible in the hands of the donors in terms of and subject to the limitations prescribed in section 18A of the Act with effect from 13 February 2018.
2. Donations made to or by the PBO are exempt from Donations Tax in terms of section 56(1)(h) of the Income Tax Act.
3. Exemption from the payment of Estate Duty in terms of section 4(h) of the Estate Duty Act No.45 of 1955.

In order to maintain your exempt status, the following conditions must be complied with:

1. Amend the constitution to comply with the requirements of section 30 of the Income Tax Act. The following clauses must be added –
 - a) At least three persons who accept fiduciary responsibility for the public benefit organisation will not be connected persons in relation to each other, and no single person directly or indirectly controls the decision making powers relating to such organisation.
 - b) Dissolution clause must be amended to state that on dissolution of the public benefit organisation, the remaining assets must be transferred to -
 - i) A public benefit organisation, which has been approved in terms of section 30 of the Act.
 - ii) Any institution, board or body which is exempt from the payment of income tax in terms of section 10(1)(cA)(i) of the Act, which has as its sole or principal object the carrying on of any public benefit activity; or
 - iii) Any department of state or administration in the national or provincial or local sphere of government of the Republic, contemplated in section 10(1)(a) or (b) of the Act.
 - c) The activities of the organisation are carried on in a non-profit manner and with an altruistic or philanthropic intent.
 - d) No activity will directly or indirectly promote the economic self-interest of any fiduciary or employee of the organisation otherwise than by way of reasonable remuneration.
 - e) The funds of the public benefit organisation will be used solely for the objects for which it was established.
 - f) No funds will be distributed to any person (other than in the course of undertaking any public benefit activity).
 - g) The public benefit organisation will not be a party to, or does not knowingly permit, or has not knowingly permitted, itself to be used as part of any transaction, operation or scheme of which the sole or main purpose is the reduction, postponement or avoidance of liability for any tax, duty or levy which, but for such transaction, operation or scheme, would have been or would have become payable by any person under this Act or any other Act administered by the Commissioner;
 - h) No resources will be used, directly or indirectly, to support advance or oppose any political party.
 - i) No remuneration will be paid to any employee, office bearer, member or other person which is excessive, having regard to what is generally considered reasonable in the sector and in relation to the service rendered and has not and will not economically benefit any person in a manner which is not consistent with its objects.
 - j) No donation will be accepted which is revocable at the instance of the donor for reasons other than a material failure to conform to the designated purposes and conditions of such donation, including any misrepresentation with regard to the tax deductibility thereof in terms of section 18A: Provided that a donor (other than a donor which is an approved public benefit organisation or an institution, board or body which is exempt from tax in terms of section 10(1)(cA)(i), which has as its sole

or principal object the carrying on of any public benefit activity) may not impose any conditions which could enable such donor or any connected person in relation to such donor to derive some direct or indirect benefit from the application of such donation.

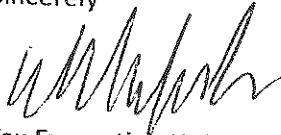
- k) A copy of all amendments to the constitution will be submitted to the Commissioner for the South African Revenue Service.
1. When issuing a tax deductible receipt it must include the following information:
 - a) The reference number (the PBO number quoted on this letter).
 - b) The date of the receipt of the donation.
 - c) The name and address of the organisation issuing the receipt to which enquiries may be directed.
 - d) The name and address of the donor.
 - e) The amount or nature of the donation if not in cash.
 - f) Certification that the receipt is issued for the purpose of section 18A and that the donation will be used exclusively for the activities which are approved for section 18A purposes.
 - g) The receipt must be issued in the year when the donation is received by the organisation approved for purposes of section 18A.
 2. Submit an annual Income Tax Return (IT12EI) by the due date via SARS e-Filing or manually. Your IT12EI can be obtained by
 - o Registering online at www.sarsefiling.co.za to access, request and submit the IT12EI electronically
 - o Calling the SARS Contact Centre on 0800 00 SARS (7277)
 - o Requesting an IT12EI by contacting the TEU on teu@sars.gov.za or calling (012) 483 1700
 - o Requesting an IT12EI by visiting your local SARS branch.
 3. Furthermore, given the section 18A approval granted, you must submit with your annual tax return, a statement and supporting documentation which include the full particulars of all the receipts issued in respect of deductible donations and how these funds were spent.
 4. The section 18A approval is ring-fenced as the organisation is carrying on the public benefit activities listed both in Part I and Part II of the Ninth Schedule to the Act. This means that:
 - a. Section 18A receipts may only be issued for those public benefit activities listed in Part II of the Ninth Schedule to the Act such as welfare and humanitarian, health care and education and development.
 - b. Section 18A receipts may not be issued for any donations received in support of activities listed in Part I of the Ninth Schedule to the Act, such as Research and Consumer rights.
 - c. The funds received for Part II activities must be kept separately from the other funds of the organisation (i.e. in a separate bank account) and recorded in separate books or accounts to be provided to SARS on request.
 - d. A certificate signed by a registered auditor, must be obtained annually and submitted to SARS on request, to confirm that all donations, for which tax-

deductible receipts were issued, were utilised exclusively for Part II activities.

5. Funds for which section 18A certificates are issued may only be used in South Africa. A certificate signed by an auditor must be submitted to SARS on request, to confirm that all donations, for which tax-deductible receipts were issued, were utilised in South Africa.
6. Tax deductible receipts may only be issued for *bona fide* donations. Refer to Annexure A for more information in this regard.
7. The exemption approval as contained in this letter is subject to review on an annual basis by the TEU upon receipt of annual income tax return and section 18A supporting documentation.
8. SARS must be informed in writing within 21 days of any change in registered particulars (e.g. Representative, change of name, address, trustee details, office bearers, etc.).

For further information or assistance, email your query to teu@sars.gov.za, visit the SARS website www.sars.gov.za, call the TEU on 012 483 1700 or visit the TEU offices. Kindly ensure that you have your ID and tax reference number on hand to enable SARS to assist you.

Sincerely



Tax Exemption Unit

ISSUED ON BEHALF OF THE COMMISSIONER FOR THE SOUTH AFRICAN REVENUE SERVICE

Annexure A: Information pertaining to S18A donations

What is considered a *bona fide* donation for S18A purposes?

A *bona fide* donation is a voluntary, gratuitous gift disposed of by the donor out of liberality or generosity, where the donee is enriched and the donor impoverished. There may be no *quid pro quo*, no reciprocal obligations and no personal benefit for the donor. If the donee gives any consideration at all it is not a donation. The donor may not impose conditions which could enable him or any connected person in relation to himself to derive some direct or indirect benefit from the application of the donation.

Examples of what does **NOT** constitute a *bona fide* donation for purposes of section 18A?

1. Donation of services rendered such as a professional person renders a skill free of charge.
2. An amount paid for attending a fundraising dinner, dance or charity golf day.
3. The amount paid for the successful bid of goods auctioned to raise funds by an organisation and Memorabilia, paintings, etc, donated to be auctioned to raise funds
4. Amounts paid for raffle or lottery tickets.
5. Amounts paid for school fees, entrance fees for school admittance or compulsory school levies.
6. Value of free rent, water and electricity provided by a lessor to the lessee which is an approved PBO.
7. Payments in respect of debt due



INCOME TAX
Notice of Registration

Enquiries should be addressed to SARS:

Contact Detail

SARS
Alberton
1528

Contact Centre Tel: 0800 00 SARS (7277)
Website: www.sars.gov.za

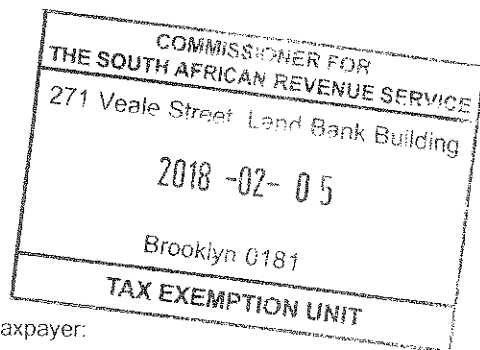
Details

Taxpayer Reference No: 9493050182

Case No: 266224316

Date: 2018-02-05

Always quote this reference
number when contacting SARS



Dear Taxpayer

NOTICE OF REGISTRATION

The South African Revenue Service (SARS) confirms registration of the following taxpayer:

Registered name: RARE DISEASES SOUTH AFRICA NPC

Taxpayer registration number: 2016/071131/08

Taxpayer reference number: 9493050182

Date of Registration: 2016-03-01

Your tax obligation

Every Company/Close Corporation which conducts business or has an office in South Africa must, within one month thereof appoint a representative as the Public Officer of the Company. The relevant particulars of the representative must be furnished to a SARS branch.

Every company is regarded as a provisional taxpayer. The Company/Close Corporation is required to make provisional tax payments as from the 2018 tax period.

Date of liability for provisional tax : 201703

Provisional payments must be made twice a year on or before the following dates: August and February

Your attention is drawn to the provisions of section 89b of the Income Tax Act and paragraph 27 of the Fourth Schedule to the Income Tax Act, in terms of which interest at the prescribed rate and a penalty of ten percent will be charged on any amount not paid on or before the date on which payment for the relevant period is due.

Kindly notify SARS of any change to your registered particulars within 21 business days of such change.

Should you have any queries please call the SARS Contact Centre on 0800 00 SARS (7277). Remember to have your taxpayer reference number at hand when you call to enable us to assist you promptly.

Sincerely

ISSUED ON BEHALF OF THE SOUTH AFRICAN REVENUE SERVICE

RFDREG L engl FV 2016.01.00 SV 1301 CT 03 NO



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