

SADS UK  
(A CHARITABLE PRIVATE COMPANY LIMITED BY GUARANTEE)

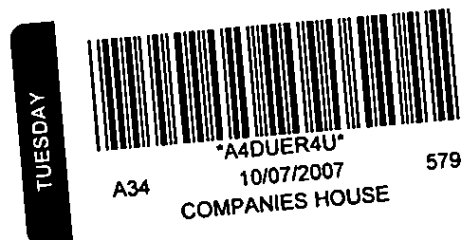
REPORT AND FINANCIAL STATEMENTS

FOR THE PERIOD ENDED

31<sup>ST</sup> DECEMBER 2006

REGISTERED CHARITY NUMBER 1113681

COMPANY NUMBER 5679989



## CONTENTS

	Page
Report of the Trustees	1 -6
Accountants' Report	7
Balance Sheet	8-9
Statement of Financial Activities	10
Notes to the Accounts	11-14



## Charity Information

<b>Trustees</b>	<p>Anne Jolly                      Chief Executive  Frank Irving                    Treasurer  John Jolly                        Secretary  Christine Carson               Director  Brenda Irons                    Director  Barrie Irons                     Director  Ann Lillis                        Director  Angela Morris                  Director</p>
<b>Patrons</b>	<p>Professor A. John Camm, FRCP  Professor G. Michael Vincent, FACC  Professor Richard Sutton, FRCP  Professor Bob Lewin, MA MPhil  Mr Kanu Nwankwo  Mark Jones  Sir Stanley Odell</p>
<b>Medical Advisors</b>	<p>Dr Andrew Grace, FRCP  Professor G Michael Vincent, FACC  Professor A John Camm, FRCP</p>
<b>Charity Registered Number</b>	1113681
<b>Principal Office</b>	22 Rowhedge, Brentwood, Essex CM13 2TS
<b>Accountants</b>	Maynard Heady, Chartered Accountants, Matrix House 12-16 Lionel Road, Canvey Island, Essex SS8 9DE
<b>Bankers</b>	Natwest, 46 High Street, Brentwood, Essex CM14 4AL
<b>Solicitors</b>	Dechert LLP, 160 Queen Victoria Street, London EC4V 4QQ
<b>Memberships to other organisations</b>	<p>Heart Care Partnership (UK)  Heart Rhythm UK  Arrhythmia Alliance  Genetic Interest Group  Medical Technology Group  Arrhythmia Awareness Week Partners  International Alliance of Patient Organisations  Council for Voluntary Services  Institute of Fundraising  British Association of Counselling and Psychotherapy</p>

Registered in England and Wales No 5679989 Registered Office 22 Rowhedge Brentwood, Essex CM13 2TS  
Registered Charity No 1113681

# Annual Report

The Trustees submit their annual report and their financial statement of SADS UK, the Ashley Jolly SAD Trust, for the year ended 31<sup>st</sup> December 2006. The Trustees confirm that the annual report and financial statement of the charity comply with the current statutory requirements, the requirements of the charity's governing document and statement of recommended practice (SORP) accounting and reporting by charities issued in 2005.

## Status

The Charitable organisation was registered in March 2000. On the 19<sup>th</sup> January 2006 the Registrar of Companies for England and Wales certified that SADS UK was incorporated under the Companies Act 1985 as a private company and that the company was limited. The company retained charitable status and the Charities Commission granted a new registered charity no 1113681.

## Memberships

See Page 1

## Charity Overview

SADS UK works to prevent Sudden Arrhythmic Death due to abnormalities of the conduction system of the heart, which may affect a person at any age, even children. Conditions covered are those such as the Long QT Syndrome, Wolff-Parkinson-White Syndrome, Brugada Syndrome, Catecholaminergic Polymorphic Ventricular Tachycardia and Arrhythmogenic Right Ventricular Dysplasia.

## The Charity's Mission Statement is

To save lives and support individuals and families who are predisposed to sudden death due to heart rhythm abnormalities (cardiac arrhythmia).

## The Charity's Vision Statement is

That GP's, primary care personnel and the general public all understand symptoms (and possible genetic implications) indicating abnormalities affecting the conduction system of the heart, appropriate diagnosis and timely treatment is undertaken and the incidence of sudden cardiac death is greatly reduced. That all primary care facilities will have heart monitoring equipment available and Automated External Defibrillators will be widely available within the community.

## Objects registered with Charities Commission

To relieve the distress of persons who have suffered from sudden bereavement or who are aware that they or a family member are susceptible to potentially sudden death through certain medical conditions, particularly, but not exclusively, by the provision of support and information and the provision of funds to supply appropriate preventative equipment (not normally met from statutory funds) to assist in diminishing the risk of sudden death.

The charity has four main objectives -

- 1 To provide support to families who have suffered a sudden and unexpected cardiac death within their family and to individuals and families who are living with abnormalities of the conduction system of the heart.
- 2 To raise awareness and educate the general public and healthcare professionals regarding cardiac conditions affecting the conduction system of the heart in order that those at risk of Sudden Arrhythmic Death (SAD) may be referred for specialist cardiac treatment.

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3. To keep up to date with medical technology and new research advances, providing equipment to organisations and health care professionals to assist with the prevention of Sudden Arrhythmic Death and supporting research
4. To guide government legislation and policy to safeguard people who may be at risk from Sudden Arrhythmic Death Syndrome if not treated

To assist with their objectives SADS UK works with other organisations. During the year the charity worked with other charities to raise awareness of Arrhythmia during Arrhythmia Awareness Week, 12<sup>th</sup> to 19<sup>th</sup> September 2006.

The launch of Arrhythmia Awareness Week took place at the Royal College of Nursing. Directors of the charity and members attended the launch, together with coroner Andrew Reid and cardiac pathologist Dr Mary Shepherd who were both invited by SADS UK.

### **NSF Chapter 8 Arrhythmias and Sudden Cardiac Death**

Arrhythmia Awareness Week 2006 focused on efficient healthcare delivery of the Department of Health guidelines, NSF Chapter 8. SADS UK Directors and members attended meetings with cardiac networks throughout the country to give their perspective.

### **NSF Chapter 8 and Patient Support**

SADS UK held their second regional patient support seminar at the Nowgen Centre in Manchester. Professor Clifford Garratt spoke about assessing relatives of victims of sudden death and Sisters Sarah Collitt and Jeanette Horsey spoke of the work they did with families who had been affected and the genetic implications.

SADS UK and their medical advisors compiled a booklet suitable for GP's and primary care personnel, containing information about NSF chapter 8 and conduction systems of the heart. The booklet was sent to over 40,000 GP's throughout the UK. Request for the booklet was made by Libraries and frontline staff at Hereford and Worcester Ambulance Service. The Ambulance Service Association circulated the booklet electronically to all NHS service UK wide.

A leaflet was developed to provide families with information about processes that may take place immediately after a sudden death and details of support available. It was felt necessary to highlight the possible hereditary implications and advise other family members to have heart checks carried out.

### **SADS UK Annual 'Lifesaving' Conference, NSF Chapter 8, Arrhythmias and Sudden Cardiac Death, Heart Rhythm Congress, Solihull 21<sup>st</sup> September.**

SADS UK continued to raise awareness and targeted doctors and primary care personnel throughout the year.

Over 40,000 invitations to the SADS UK conference were sent to doctors throughout the UK, which brought about good doctor attendance to the conference.

The conference hosted a collaboration of healthcare professionals, together with managers tasked with healthcare delivery of NSF Chapter 8.

Cardiologists in this field gave details of the cardiac conditions and therapies available for treating them. A cardiovascular geneticist discussed the work being carried out at the Oxford Genetics

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Knowledge Park with regard to developing routine clinical testing for inherited cardiomyopathies and the Long QT Syndrome. A leading pathologist advised of the need for accurate post mortem examination and how important correct death verdicts are for surviving members of the family. The Chief Executive spoke of the support needs of families that the charity represents. The Department of Health Programme Manager for the implementation of NSF Chapter spoke about healthcare delivery and the progress to date of the cardiac networks who are working to achieve this.

The monitoring of cardiac conditions in primary care was also discussed, including effective ways in which some doctors are working with cardiologists to obtain accurate interpretation of ecg's taken in primary care.

Mike Yates, Department of Health National Programme Manager Chapter 8, updated attendees on the progress of Chapter 8.

### **Heart Monitor Placements**

SADS UK provides equipment to GP's to help them identify patients with abnormalities of the heartbeat. To date SADS UK have donated over sixty, 24 hour heart monitors to doctors surgeries and health centres around the country. These machines are in an environment where they can be used at any time and on any individual where the practitioner suspects a problem during a typical GP appointment, no special clinic appointment is necessary. The monitor is endorsed by leading cardiologists and allows GP's to make informed referrals to hospital significantly reducing cardiology appointments, which allows those at risk to be assessed more readily. If these monitors are used on average only three times a week, 7,500 extra patients are assessed for heart conditions annually.

Feedback to SADS UK has shown that the heart monitors are easy to use and convenient. Patients with life-threatening rhythm abnormalities can be identified quickly and referred on for specialist checks. Patients with innocent conditions are quickly reassured.

Fourteen heart monitors were donated over the last financial year.

### **Automated External Defibrillator Placements**

Fourteen defibrillators were donated over the last financial year.

### **Research**

Subsequent to the SADSUK/Oxford Genetics Knowledge Park conference last year some members took part in clinical testing at the Oxford Genetics Knowledge Park.

SADS UK supported the Helen Kirkland Cardiac Arrhythmia Research Fund for research into cardiac arrhythmia at Papworth Hospital, Cambridge.

### **Raising Awareness and Fundraising**

The charity raises awareness through educational conferences, hard copy leaflets, posters, booklets and well-publicised information. The website was redesigned to make it easier to navigate the website and access information. There were many reports about Sudden Arrhythmic Death Syndrome (SADS) in the media, brought about by the charity and its membership, with a concerted effort made during arrhythmia awareness week.

Very many fundraising events took place throughout the year. Funds were raised through a variety of different events held throughout the country. Events ranged from the more adventurous skydive to the more homely coffee morning. Many sponsored events took place throughout the year.

## **Patient Support**

QT Koala, the charity's furry support friend, sent to the UK as a gesture of friendship and support from the Australian SADS Foundation, continued to travel to family's in the UK for them to share their experiences of living with the Long QT syndrome. Families were able to read Koalas journal and add their own thoughts and adventures for others to read when they hosted QT Koala.

The patient support seminar held in Manchester in April gave members the opportunity to meet together and share experiences.

SADS UK kept its membership and supporters up to date with developments in cardiac care and activities of the charity, seeking opinions and sharing articles through the SADS UK Newsletter, Sensitive Hearts.

## **Acknowledgements**

SADS UK thanks all those who so generously gave their support during the financial year. Without this funding and support SADS UK would not achieve its aims and objectives.

## **Appointment of the Trustees**

As set out in the Articles of Association the membership is open to individuals or organisations who apply to the Charity in the form required by the Directors and are approved by the Directors.

## **Trustees Induction and Training**

New trustees undergo an orientation day to brief them on their legal obligations under charity and company law, the content of the Memorandum and Articles of Association, the committee and decision making processes, the business plan and recent financial performance of the charity. During the induction day they meet key employees and other trustees. Trustees are encouraged to attend appropriate external training events where these will facilitate the undertaking of their role.

## **Financial Review and Risks**

The trustees have established a level of reserves (that is funds that are freely available) that the charity ought to have. Reserves are needed to bridge the funding gaps between spending on projects that are receiving resources through donations and fund raising.

During the year all funds from The Ashley Jolly Trust were transferred to the new company. Total income for the period amounted to £106,235. Expenses totalled £107,434, producing a net expenditure of £1,199. Total reserves at 31<sup>st</sup> December 2006 were £142,875, of these £98,143 were unrestricted funds. The Directors consider this to be an adequate level of reserves.

The trustees have a risk management strategy which comprises

- An annual review of the risks the charity may face,
- The establishment of systems and procedures to mitigate those risks identified in the plan,
- The implementation of procedures designed to minimise any potential impact on the charity should those risks materialise.

This work has identified only a few minor risks but it has resulted in better emergency procedures and contingency plans and has given the impetus for better planning. A key element in the management of financial risk is the setting of a reserves policy and its regular review by trustees.

## **Investment Powers and Policy**

Under the Memorandum and Articles of Association, the charity has the power to invest in the same manner and subject to the same conditions as the trustees of a trust are permitted to do by the Trustees Act 2000

The trustees, having regard to the liquidity requirements of the charity and reserves policy, have operated a policy of keeping available funds in an interest bearing deposit account and seek to achieve a rate of deposit interest which matches or exceeds inflation

## **Trustees' Responsibilities in Relation to the Financial Statements**

Company law requires the trustees to prepare financial statements that give a true and fair view of the state of affairs of the charity at the end of the financial period and of its surplus or deficit for the financial period. In doing so the trustees are required to

- Select suitable accounting policies and then apply them consistently,
- Make sound judgements and estimates that are reasonable and prudent, and
- Prepare the financial statements on the going concern basis unless it is inappropriate to presume that the charity will continue in business

The trustees are responsible for maintaining proper accounting records which disclose with reasonable accuracy at any time the financial position of the charity and enables them to ensure that the financial statements comply with the Companies Act 1985. The trustees are also responsible for safeguarding the assets and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities

## **Independent Examiners**

A resolution will be proposed at the Annual General Meeting that Maynard Heady be re-appointed as independent examiners to the charity for the ensuing year

By order of the trustees



J Jolly (Chairman)



**SADS UK**  
**(A COMPANY LIMITED BY GUARANTEE)**  
**CHARITY NUMBER 1113681**  
**ACCOUNTANTS REPORT FOR THE PERIOD ENDED**  
**31ST DECEMBER 2006**

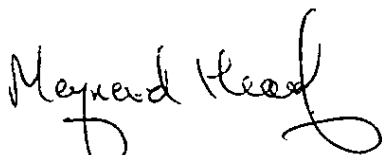
In accordance with the engagement letter dated 27th March 2007, and in order to fulfil your duties under the Companies Act 1985, we have compiled the financial statements of the charitable company (the company) on pages 15 to 21 from the accounting records and explanations you have given us

This report is made to the Charity's Board of Directors as a body, in accordance with the terms of our engagement. Our work has been undertaken so that we might compile the financial statements that we have been engaged to compile, report to the Charity's Board of Directors that we have done so, and state those matters that we have agreed to state to them in this report and for no other purpose. To the fullest extent permitted by law, we do not accept or assume responsibility to anyone other than the Charity and the Charity's Board of Directors as a body, for our work or for this report.

We have carried out this engagement in accordance with technical guidance issued by the Institute of Chartered Accountants in England and Wales and have complied with the ethical guidance laid down by the Institute relating to members undertaking the compilation of financial statements.

You have acknowledged on the balance sheet for the period ended 31st December 2006 your duty to ensure that the charity has kept proper accounting records and to prepare financial statements that give a true and fair view under the Companies Act 1985. You consider that the charity is exempt from the statutory requirement for an audit for the period.

We have not been instructed to carry out an audit of the financial statements. For this reason, we have not verified the accuracy or completeness of the accounting records or information and explanations you have given us and we do not, therefore, express any opinion on the financial statements.



MAYNARD HEADY  
CHARTERED ACCOUNTANTS  
12 - 16 Lionel Road  
Canvey Island  
Essex SS8 9DE

11/6/07.

Date

SADS UK

BALANCE SHEET AS AT 31ST DECEMBER 2006

2006

£

CURRENT ASSETS

Cash at bank and in hand

Unrestricted funds

Current account nos 53571746 and 77056965	4,419 63
Capital reserve accounts	95,484 72
	<u>99,904 35</u>

Restricted funds

Kimberley Robinson Memorial Account	3,455 54
Francean Buckland Memorial Account	275 28
Tony Hughes Memorial Account	4,802 41
Richard Hellyer Memorial Account	1,017 75
Andrew Mortlock Memorial Account	1,329 40
Ben Hoare Memorial Account	5,199 03
Ria Hickerton Memorial Account	3,432 80
P Carder and Ryan Bothamley fund	1,435 16
B Hargis fund	2,570 00
Mike Taylor Fund	2,582 58
Chris Peill Memorial Account	2,282 00
Richard Abbott Memorial Account	4,083 23
David Irons Memorial Account	114 21
Bill Preest Memorial Account	2,950 06
Joe Riley Memorial Account	4,013 60
Paul Marsden Memorial Account	1,486 55
Joc Spencer Memorial Account	2,823 24
Colin Meyer Memorial Account	679 91
Daniel Boughcy Memorial Account	200 00

CURRENT LIABILITIES

Accruals	(1,762 50)
	<u><u>£142,874 60</u></u>

REPRESENTED BY

Accumulated fund

Funds transferred from Ashley Jolly SAD Trust	144,074 50
Net Expenditure for the period	(1,199 90)
Accumulated fund carried forward	<u><u>£142,874 60</u></u>

SADS UK

BALANCE SHEET AS AT 31ST DECEMBER 2006

(CONTINUED)

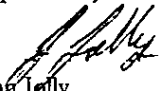
In preparing these financial statements -

- (a) The directors are of the opinion that the company is entitled to the exemption from audit conferred by Section 249A (1) of the Companies Act 1985,
- (b) No notice has been deposited under Section 249B (2) of the Companies Act 1985, and
- (c) The directors acknowledges their responsibilities for
  - (i) ensuring that the company keeps accounting records which comply with Section 221 of the Companies Act 1985, and
  - (ii) preparing accounts which give a true and fair view of the state of affairs of the company as at the end of the financial period and of its profit or loss for the financial period in accordance with the requirements of Section 226, and which otherwise comply with the requirements of this Act relating to accounts, so far as applicable to the company

These financial statements have been prepared in accordance with the special provisions of Part VII of the Companies Act 1985 relating to small companies and with the Financial Reporting Standard for Smaller Entities (effective January 2005)

Approved by the Board for issue on

11/6/07

  
John Jolly  
Director

**SADS UK**

**(REGISTERED CHARITY NUMBER 1113681)**

**INCOME AND EXPENDITURE ACCOUNT AND STATEMENT OF FINANCIAL ACTIVITIES**

**FOR THE PERIOD ENDED 31ST DECEMBER 2006**

	Unrestricted Activities	Restricted Activities	Total Funds 2006
<b>INCOMING RESOURCES / INCOME</b>			
Voluntary Income	76,591	20,012	96,603
Activities for generating funds	4,722	2,353	7,075
Investment Income	2,232	325	2,557
	<u>83,545</u>	<u>22,690</u>	<u>106,235</u>
<b>RESOURCES EXPENDED / EXPENDITURE</b>			
Costs of generating voluntary income	4,859	-	4,859
Fundraising trading costs	6,253	-	6,253
Investment management costs	7	-	7
Charitable expenditure	57,016	5,975	62,991
Governance costs	33,324	-	33,324
<b>Total resources expended</b>	<u>101,459</u>	<u>5,975</u>	<u>107,434</u>
<b>NET (EXPENDITURE)</b>	(17,914)	16,715	(1,199)
Total funds brought forward	116,057	28,017	144,074
<b>Total funds carried forward</b>	<u><u>98,143</u></u>	<u><u>44,732</u></u>	<u><u>142,875</u></u>

**SADS UK**

**REGISTERED CHARITY NO 1113681**

**NOTES TO THE ACCOUNTS FOR THE PERIOD ENDED 31ST DECEMBER 2006**

**1 BASIS OF PREPARATION**

**1.1 Basis of accounting**

These accounts have been prepared on the basis of historical cost in accordance with -

- Accounting and Reporting by Charities - Statement of Recommended Practice (SORP 2005),
- and with Accounting Standards,
- and with the Charities Act 1993,
- and with the Companies Act 1985 as applicable to small companies

**1.2 Change in basis of accounting**

There has been no change to the accounting policies (valuation rules and methods of accounting) since last year

**1.3 Changes to previous accounts**

No changes have been made to the accounts for previous years

**2. ACCOUNTING POLICIES**

**INCOMING RESOURCES**

Recognition of incoming resources

These are included in the Statement of Financial Activities (SoFA) when

- the charity becomes entitled to the resources,
- the trustees are virtually certain they will receive the resources, and
- the monetary value can be measured with sufficient reliability

Incoming resources with related expenditure

Where incoming resources have related expenditure (as with fundraising or contract income) the incoming resources and related expenditure are reported gross in the SoFA

Grants and donations

Grants and donations are only included in the SoFA when the charity has unconditional entitlement to the resources

Donated services and facilities

These are only included in incoming resources (with an equivalent amount in resources expended) where the benefit to the charity is reasonably quantifiable, measurable and material. The value placed on these resources is the estimated value to the charity of the services or facility received

Volunteer help

The value of any voluntary help received is not included in the accounts but is described in the trustees' annual report

Investment income

This is included in the accounts when receivable

**EXPENDITURE AND LIABILITIES**

Liability recognition

Liabilities are recognised as soon as there is a legal or constructive obligation committing the charity to pay out resources

**SADS UK**

**REGISTERED CHARITY NO 1113681**

**NOTES TO THE ACCOUNTS FOR THE PERIOD ENDED 31ST DECEMBER 2006**

**3 ANALYSIS OF INCOMING RESOURCES**

	Unrestricted Activities £	Restricted Activities £	2006 Total £
<i>Voluntary Income</i>			
Income - medical equipment	24,799	-	24,799
Donations	43,173	20,012	63,185
Conference income	8,205	-	8,205
Membership fees	414	-	414
	<u>76,591</u>	<u>20,012</u>	<u>96,603</u>
<i>Activities for generating funds</i>			
Christmas card sales	2,203	-	2,203
Quiz income	2,329	-	2,329
Income from Barbeque	190	-	190
Other fundraising	-	2,353	2,353
	<u>4,722</u>	<u>2,353</u>	<u>7,075</u>
<i>Investment income</i>			
Bank interest received	<u>2,232</u>	<u>325</u>	<u>2,557</u>
<b>TOTAL</b>	<u>83,545</u>	<u>22,690</u>	<u>106,235</u>

**SADS UK**

**REGISTERED CHARITY NO 1113681**

**NOTES TO THE ACCOUNTS FOR THE PERIOD ENDED 31ST DECEMBER 2006**

**5 PAID EMPLOYEES**

**2006**

**5.1 Staff costs**

**Total**

Gross wages, salaries and benefits in kind

25,303

**5.2 Average number of full-time equivalent employees in the year**

The parts of the charity in which the employees work

Governance

1

No employees have remuneration of £60,000 or above

**6 INDEPENDENT EXAMINERS FEES**

**2006**

Independent examiners remuneration

1,762