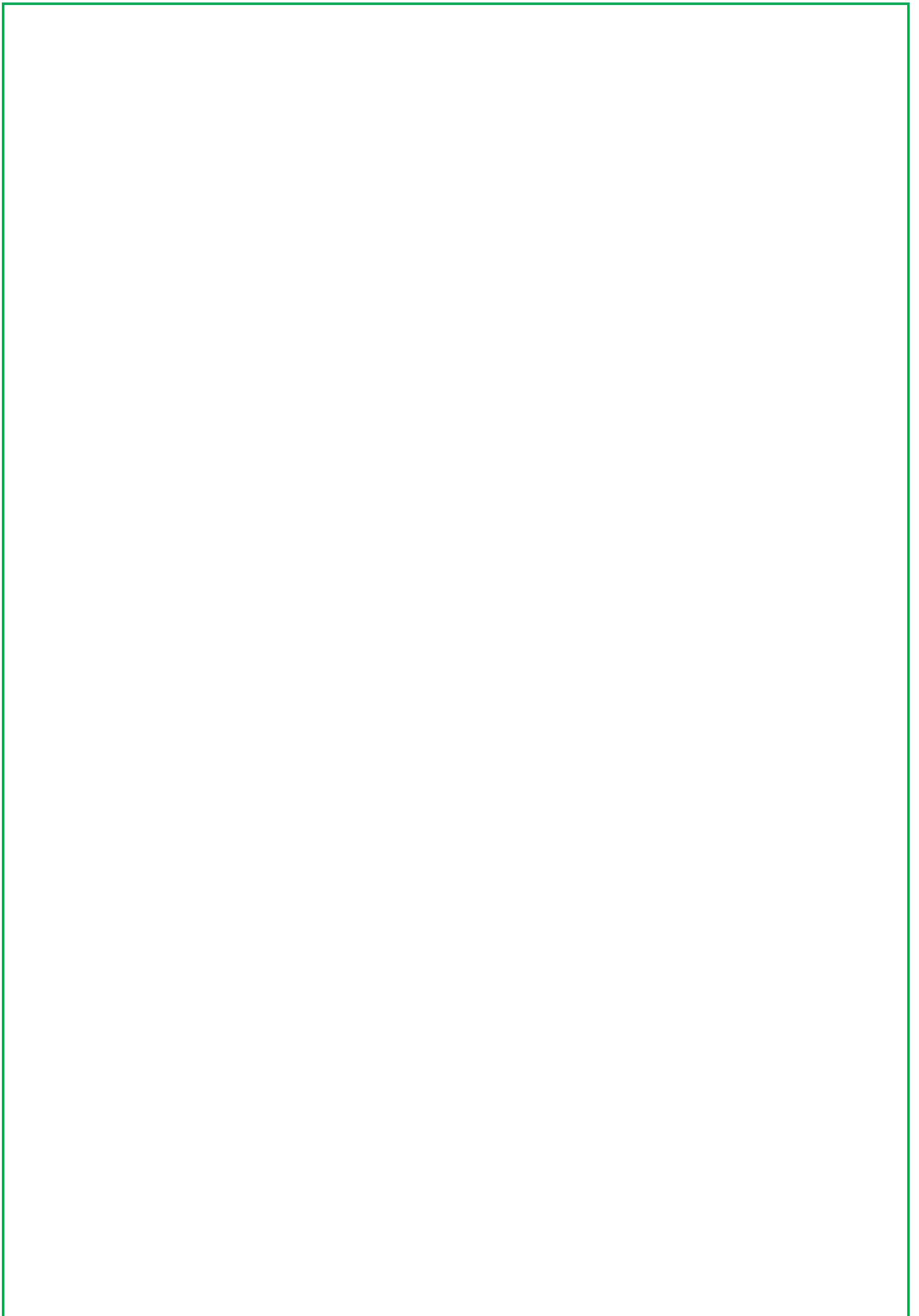




Australian
Huntington's
Disease
Association
(NSW) Inc.

Annual Report

2013 – 2014



Australian Huntington's Disease Association (NSW) Inc

Trading as Huntington's NSW

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Bankers: Commonwealth Bank of Australia, Sydney NSW
St George Bank Limited, Kogarah NSW

Auditor: Thomas GLC Chartered Accountants
PO Box 1563 Hornsby NSW 1635

Other Information: Australian Business Number (ABN) 54 571 730 306
Endorsed as a deductible gift recipient and income tax exempt charitable entity; registered for GST
Incorporated in NSW, 1993 Registered No. Y16575-09
Authority to Fundraise in NSW Number CFN13153
Licence for Conducting Charitable Collections in the ACT Number 19000322

Public Officer: Robyn Kapp OAM

Board Members

The board members of the Association who held a position during the financial year 2013/2014 were:

President:	Brian Rumbold
Vice President:	Deborah Cockrell
Secretary:	Don Ayres
Treasurer:	Richard Bobbitt
Board members:	Jenny Coutts Amanda Dickey

Association Staff

The members of staff employed by the Association during the 2013/2014 financial year were:

Executive Officer:	Robyn Kapp OAM
Administration Officer:	Margaret Lind (<i>commenced 4th February 2014</i>)
Family Support Worker:	Mark Bevan
Administrative & Activities Assistant	Shu Yue (Lily) Ma (<i>resigned 23rd December 2013</i>)
Activities Assistant:	Karen Bevan (<i>commenced 28th January 2014</i>)

Our Mission

The energies and resources of the Association are directed towards satisfying the needs of people with or at risk for Huntington's Disease and their families in NSW and the ACT by providing and/or facilitating delivery of a range of quality services.

Our Philosophy

The philosophy underlying all our services encompasses the principle that people with Huntington's Disease and their families are individuals with equal value to all other members of Australian society, with the right to treatment and care by knowledgeable professionals and care givers, the right to appropriate support services and the right to have the best quality of life possible.

From the President

The past year presented itself needing some hard work without necessarily seeing substantial rewards at the end. It was, in fact, a year of long term planning.

In April the Board held a strategic planning day to develop the framework of a plan which will be completed in 2014/2015. The framework for our future development focusses on four main areas:

- Education and Information – Providing information and education for the Huntington community and health professionals through both distribution media (phone, mail, web, email) and group events (such as workshops and seminars).
- Family Support – Visiting HD families, especially in regional and rural areas, to provide information and support at a personal level; sponsoring or organising carer and family support groups and youth programs.
- Events and Activities – Organising and facilitating community events and activities such as: family days, lunch and social clubs, holiday camps.
- Advocacy – Challenging the current state of affairs with an informed critique, and promoting well researched and intelligent solutions aimed at addressing needs and improving the HD community's wellbeing.

As different opportunities arise, we will be able to use our plan to guide us as we turn ideas and proposals into activities and programs.

Of course, to turn our plans into actions we need more consistent funding. We have recognised that we need a more strategic approach to funding Huntington's NSW, which means thinking more broadly about funding in general by

- Securing our current grants in the medium term
- Finding new sources for grants
- Having a more systematic approach to fundraising.

In the last year we have focused on developing our approach to fundraising and I believe we are beginning to see the fruits of this planning now and we look forward to building on it throughout the current year.

On behalf of the Board, I would like to thank all who have generously supported the Association throughout the year. I also want to thank the members of the Board for their involvement and contributions over the last year, and our staff for their commitment and hard work. We look forward to continuing to serve the Huntington's community in the year ahead.

Brian Rumbold
President

From the Executive Officer

Families impacted by Huntington's disease (HD) have been the main focus of Huntington's NSW for the past 39 years. We move towards 2015 – our 40th anniversary year – as a stronger support organisation with our focus firmly fixed on families. This is evident in the strategic plan and priorities that the Board has developed for the coming year.

Planning the strategic direction of the Association's activities is a major component of the Board's role. The purpose of strategic planning and prioritising in any organisation is to ensure that existing services, identified as appropriate and relevant to members, are built upon and that new services are established where a need is demonstrated.

With this in mind, Huntington's NSW is determined to provide a range of quality services and programs for those affected in any way by HD. This is already evident in our Lunch Club, Holiday and Family Support programs. However, it is also important that the quality of these programs be reviewed in consultation with our clients and their families, health professionals and supporters to make sure they remain relevant and effective to all involved.

I would like to take this opportunity to thank our staff – although small in number – their commitment and hard work are to be applauded. I would also like to thank the Board and, in particular, our President, Brian Rumbold for his immeasurable contribution to and enthusiasm for Huntington's NSW. Without such dedicated people, we would not be where we are today.

*Robyn Kapp OAM
Executive Officer*

Highlights of 2013-2014

Education and Information

- The main source of information on all aspects of Huntington's disease is now our website with all publications now available to download. There were over 23,000 visitors to our site in 2013-2014. We are most grateful to Jason Turnbull from Digiscape for his input and advice. The website maintains accreditation with external government reviewers (The HONcode standard for trustworthy health information.) in relation to its health and medical content. All publications are still available as hard copy.
- The four editions of our newsletter, *Gateway*, published over the past twelve months covered a range of informative subjects of which the research updates are of particular interest and encouragement to families. The print version still proves to be more popular than the electronic version with an average of 300 copies sent via mail and 160 sent electronically. The newsletter is uploaded to the website and is included in information packs in response to requests for information. Anecdotal feedback concerning the content continues to be very positive.
- The Association continues to support HDBuzz, a website that features up-to-date scientific research news on Huntington's disease, written in plain language by scientists. This website also provides invaluable material for the newsletter.

Services for Clients

- Two holiday camps were held with 8 people attending each camp. Camp Breakaway, with its well laid out grounds and amenities continues to prove to be an ideal location for the Association's Holiday Program. This program is one of the Association's longest running and consistently well-received services.
- The Social /Lunch Club was held on nineteen occasions during 2013-2014 with an average of 5 people attended on each occasion. The group enjoys a wide range of activities including word and card games and, of course, a delicious lunch. There is room for more participants however the major obstacle facing those who are interested is transport.
Six genetic counselling students attended Lunch Club during the year as part of community service which is a requirement of their training.
- In a joint venture with the HD Youth Forum we held a Family Fun Day in July 2013 at Bicentennial Park. Over 40 people enjoyed a fun-filled day with lots of activities for the kids and a sausage sizzle lunch. It was also a wonderful opportunity for the adults to chat with one another and to make new friendships and share experiences.
Huntington's NSW continues to support HDYO, the international website for young people impacted by Huntington's disease. The goal of HDYO is to empower youth with knowledge about HD and provide a supportive community to help each other cope with realities of the disease.

Family Support

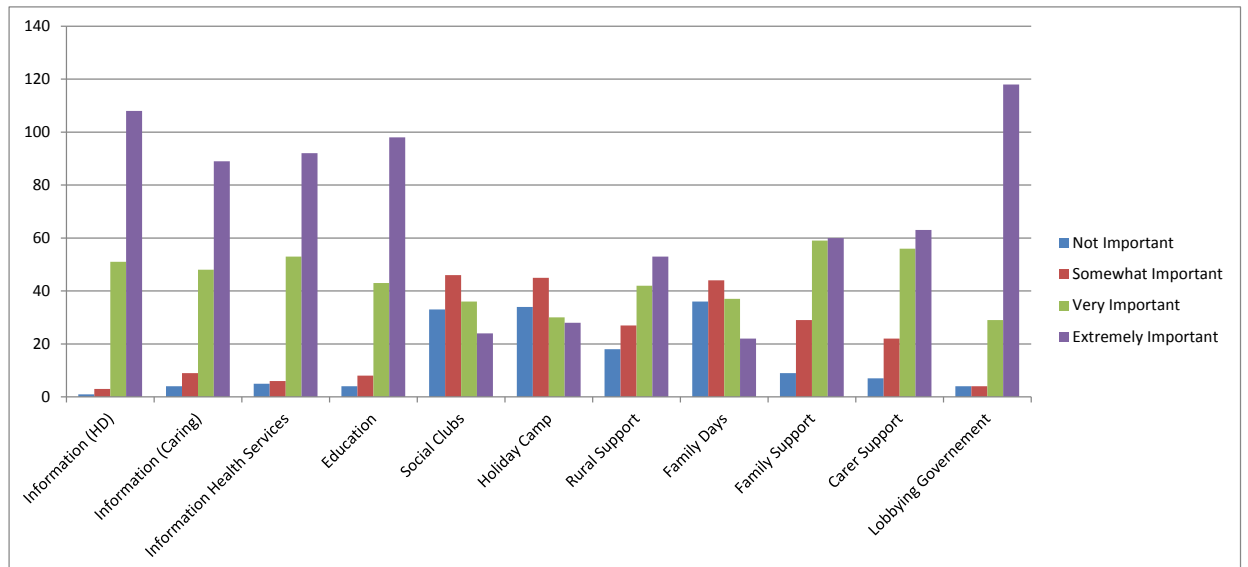
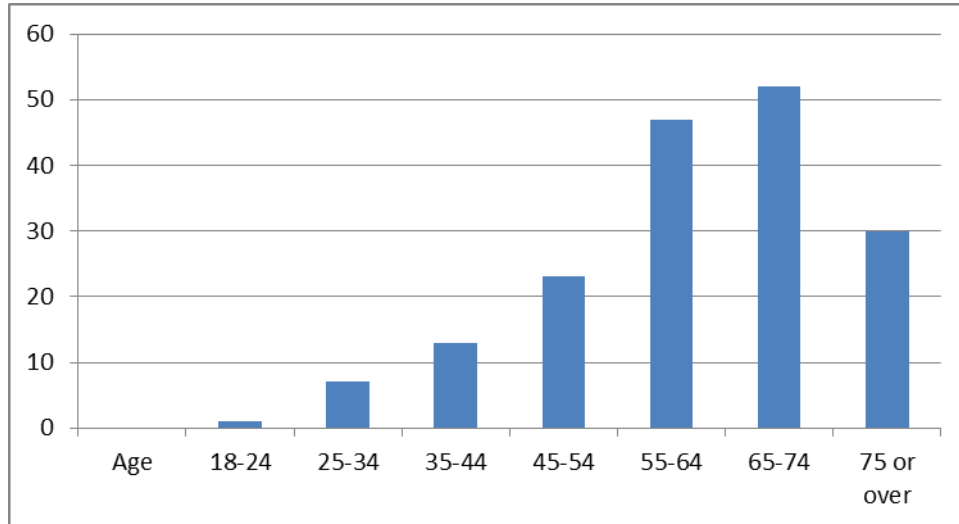
- During 2013/2014 we provided information, support and referral to family members, people with HD or at risk for HD and health professionals. Contact is made either via telephone or email. Where necessary the caller may be referred to the HD Service at Westmead Hospital, Genetic Clinics at major hospitals or to our Regional Family Support Worker.
- Mark Bevan, our Regional Family Support Worker, covers rural NSW and the ACT. During regional visits Mark attended and facilitated group meetings, undertook family visits, nursing home presentations and met with health professionals. He had contact with 57 new clients and 20 new health professionals over the period; he undertook 10 in-service sessions for health professionals with an average of 11 attendees at each session; and he attended a total of 10 support group meetings on the Central Coast, Mid North Coast and the ACT. The average attendance at each meeting was 12.

Region	Number of trips		Number of client visits		Number of clients seen		Number of client contacts Phone, email, etc	
	2012/13	2013/14	2012/13	2013/14	2012/13	2013/14	2012/13	2013/14
North West	2	2	15	15	33	20	91	161
North coast	1	2	18	26	54	52	128	341
South coast	2	2	22	25	55	55	137	164
South west	2	2	36	31	70	51	218	301
West	2	2	29	27	73	46	215	252
Mid north coast	1	2	11	11	26	19	230	126
Hunter	Ad hoc		3	3	6	6	66	92
ACT	1	2	0	0	0	0	99	109
Central Coast	Ad hoc		16	18	36	38	301	351
TOTALS	11	14	150	156	353	287	1485	1897

- The Central Coast Support Group continues to serve the people of that area well. Average attendance at the monthly meetings was 13. During the 2013 federal election campaign the group had an online petition advocating for better services for HD families on the Central Coast. The federal member for Robertson, Ms Lucy Wicks, attended the April 2014 meeting to listen to the concerns of families. A small and committed group of carers also meets on a monthly basis.
- The Association hosted the metropolitan Family and Friends Support Group each month at its premises in West Ryde. This group is facilitated by the Social Workers from the NSW HD Service and the average attendance was 8 people each month.

Survey

One hundred and seventy three (173) people responded to the survey held in the reporting period. Of these 105 were female and 66 were male with the majority of respondents being over the age of 55.



Fundraising, Grants and Donations

- Fundraising and government grants realise the major portion of our income. The recurring NGO from NSW Health continues to increase in line with the CPI.
- We received a grant of \$3,385 from the NSW Community Building Partnership to replace the blinds in Elsie Court Cottage. We are most grateful to Victor Dominello, MP, Member for Ryde who recommended that we receive this finding.
- The donations and fundraising of members and supporters continue to be a valuable source of funding for the Association. We are grateful to those who held fundraising events and those who participated in the City to Surf, the Canberra Fun Run and the Sydney Rebel Run. We would like to particularly acknowledge Margaret Bain-Smith and Don Ayres (Concord Rotary Golf Day); Matina Moutzouris (Book Fair); Terry Ayres (High Tea and WOW Designer Jewellery); and the Central Coast Support Group.
- This year also saw the beginning of our relationship with Salvos Stores and we are indebted to Neville Barrett and Freddy Woo for their commitment to our cause.
- After careful consideration the Board agreed to engage the services of Pauline Keyvar from Fundraising and Mentoring Solutions Pty Ltd (FAMS). Pauline is the principal fundraising consultant at FAMS and has spent more than 20 years developing and implementing fundraising strategies and programs for a range of not for profit organisations. The first steps included consolidating our data into one system and establishing a base for implementing and developing a fundraising business plan.

Special Acknowledgements

The Association acknowledges the following with sincere appreciation for their contributions throughout the year:

- NSW Health for its ongoing partnership through its NGO Program.
- NSW Family & Community Services for its support through its Carers Program.
- The Department of Premier & Cabinet for its support through its Community Building Partnerships Grants Program.
- The Member for Ryde, Mr Victor Dominello, MP
- Carers NSW
- Our donors, those who have undertaken fundraising events or supported our telemarketing program throughout NSW and the ACT.
- Organisations and health professionals who have worked alongside HNSW to provide services and support for people living with HD and their families.
Particular thanks go to:
 - Dr Clement Loy, Director, NSW HD Service, Westmead Hospital;
 - Jet Aserios, Cecelia Lincoln, Colleen McKinnon, Mark Cirillo and the staff of the NSW Huntington Disease Service;
 - Dr Elizabeth McCusker and the Research Team, Westmead Hospital;
 - Fiona Richards, Predictive Testing Program, Children's Hospital, Westmead;
 - John Conaghan, Hunter Genetics;
 - Sister Maria Cunningham Centre and St Joseph's Hospital, Auburn.

