



*National Clinic in Nottingham for  
Ataxia-Telangiectasia*

*The Ataxia-Telangiectasia Society  
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*Reg. Charity No. 1105528*

## Introduction

The Clinic was launched in October 1993 as a direct result of an initiative by the A-T Society. A-T is a very rare disease. The need to establish a Clinic where clinical expertise, knowledge of the disease and management of the condition could be built up was seen as a high priority in order to improve quality of life and length of life. The Society continues to fund the Clinic.

The Clinic is held 3 times a year, currently on a Friday.

## Main Aims

- To provide information on all aspects of A-T based on the needs of the individual, the family and the local care team.
- To provide a comprehensive written report, for the family and local care team within approximately 6 weeks (this varies depending on the need to wait for results) with advice regarding appropriate management strategies.
- To provide a named contact for every family who attends - Dr Mohnish Suri.
- To promote clear, effective and positive communication with the local care teams.
- To aid research.
- To operate in an interdisciplinary and reflective manner.

To achieve this:

1. Team members meet before and after each Clinic.
2. A questionnaire is given to families after each Clinic.
3. A 'Review Day' is held at least once a year to consider clinical procedure and practices as well as future developments.

## The Team

The Clinic is under the direction of Dr Mohnish

Suri, Geneticist. The team also involves a Neurologist, Immunologist, Physiotherapist, Occupational Therapist, Speech & Language Therapist, Dietitian, Physiologist and Genetic Counsellor.

Kay Atkins, Family Support Worker, attends to meet families and discuss any issues you may have. Professor Malcolm Taylor who is known to most of you and who has been at the frontier of A-T research for many years also attends when he can.

## Referrals and Reviews

The Clinic is happy to see any family which has a child diagnosed with A-T. There may be a wait of a few months for the initial appointment but the aim is to see anyone who has recently been diagnosed as soon as the family feel they wish to attend. Although most referrals come through the A-T Society, the Clinic also receives and welcomes referrals from Paediatricians, Neurologists, GPs and other professionals involved with the family.

## The Patient Hotel

It is appreciated that for many families a visit to the Clinic involves much travel. Several have made use of the Patient Hotel on the hospital campus for the night prior to their appointment. Feedback about this has been very positive. Details are sent out with appointments.

Should any family need assistance with travel and/or the patient hotel costs, they should contact the A-T Society.

## Family Days and the Clinic

Members of the Clinic team attend the Family Day each year to provide updates of generalised experiences and progress (obviously patient confidentiality is always maintained).

**With grateful thanks to Dr Susan Ritchie**

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## **The Ataxia-Telangiectasia Society**

### **Supporting the Family—Fighting the Disease**

**The Ataxia-Telangiectasia Society** is a national charity. Our objective is to alleviate the suffering and distress that A-T causes. We do this by:

- Supporting families
- Improving clinical management through two specialist clinics
- Providing information on the disease and raising awareness
- Funding research

**We rely totally upon voluntary donations to continue our work.**