

# Annual Report 2007

# Nystagmus Network

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# 2007 at a glance

## Enquiries

2007

From families and individuals	380
From professionals	199
Other	84

## Website statistics

2007

2006

Visitors	329,916	215,029
Forum new users	291	119
Sales through online shop	£6,220	£6,217

## Financial highlights

2007

2006

Income	£53,400	£52,000
Expenditure	£38,400	£38,900

## Research funding

2007

Support for genetic research in Southampton	£5,000
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## Events attended:

- Sight Village Exhibition, Birmingham
- REVEAL Exhibition, Leeds
- Sight and Sound Exhibition, Glasgow
- RNIB Low Vision Exhibition, Nottingham
- Peripatetic VI Education Service Day, Lincoln

## Nystagmus Network training and awareness raising events:

- March – training day for teaching assistants with Richmond LEA
- April – awareness raising session for Gwent Association for the Blind
- June – training for ophthalmology department, Southampton
- October – training for specialist teachers at Henshaw's College, Liverpool
- November – training for FE Support staff at West Notts College, Mansfield
- November – nystagmus training day for QTVI teachers, Birmingham

## In 2007 we also ...

- Contributed to the UK Vision Strategy document
- Published four issues of our Focus newsletter (circulation 800 plus)
- Developed a five year strategic plan

## ... and in 2008

- We will hold our Open Day in Nottingham for the first time
- Launch our children's book "Tales of Northwick" on audio CD

# President's report

Incredibly, we began work in 2007 for our SECOND international research workshop.

I say incredibly because it seemed to me to be only the other day when we held the world's first nystagmus workshop at Cosener's House in Abingdon. I find it hard to believe it was actually September 2005 when leading experts travelled from many different parts of the world to debate, and occasionally duel over, the baffling challenge of nystagmus.

At the end of that very memorable event, we asked the experts whether they thought another such event could be useful, and to a last man and woman they said "yes" – in about four years, to allow ideas and partnerships developed at that first session time to grow and produce results.

We learned first time round how long it takes to organise such an event – and to raise the money to support it. So we decided to start early and in summer 2007, we began to plan for September 2009. We assembled our experts and our organisers, and began the task of deciding what we should do, and how.

A critical issue for us is not simply to repeat the first event. We know that the 2005 seminar filled an entire supplement of a leading US ophthalmology publication with its papers and presentations; led to a number of research collaborations; and (anecdotally) inspired younger practitioners to see nystagmus research as a critical area for future development. This latter aspect is critical if we are to develop a larger research community around the world.

We also know that, for the first time, there was focused discussion between the world's leading experts about possible routes to treatment – and an expectation that, at a future event, we would hear much more about the results of early research.

## Wider remit

In January 2008, I chaired a special meeting of medical and research experts - plus our dedicated organising group - to put together an agenda for the 2009 event. We agreed, after discussion with our experts, to expand the breadth of the 2009 event to include acquired nystagmus as well as congenital nystagmus. This is because our experts believe research based on investigation of how nystagmus is acquired is likely to provide important and fruitful areas of research for all those who suffer with the condition and its associated problems.

We also decided that, next time, session leaders will be asked to provide us with their presentations before the event so we can compile the book we have decided will be published as soon as possible after the workshop. We already know that important research findings will be presented at this conference, so we can anticipate many months before it actually happens that this is going to be a significant conference for experts in the field.

If you are reading this in our annual report, please ask yourself how you can help this important process. As I write, we are preparing to write to Trusts and Foundations to seek their financial support, but we are also going to ask our membership to help us too. Altogether, we now know we will need about £40,000 for the

workshop and the book. It doesn't matter how small the donation, it all helps.

For our part, we will keep you fully informed about our progress. Read our website for regular updates. And we will feedback the headlines from the event itself as swiftly as we can.

It has only just dawned on me that the conference will take place in our 25th year, so I hope we will have much to celebrate.

**Vivien Jones, honorary president**

## Chairman's report

In 2007 the NN Committee focused on improving member benefits, our strategic development and preparing for our second international scientific workshop.

Our 2007 Open Day was one of the best attended and well received we have ever achieved. We worked in partnership with the Albinism Fellowship, National Blind Children's Society and LOOK with an emphasis on workshops, open discussion and fun for young people and children. The aim of the day was to get as much discussion going between members as possible and we could not have been more pleased with the outcome.

### Strategic plan

We now have in place a Strategic Development Plan for 2008-12 with a supporting Implementation Action Plan much of which is already in progress. Our vision is a world where everyone with nystagmus, and their families, has the support and information they require; a world where the scientific and medical community has a full understanding of the causes, prevention and cure of nystagmus.

Our mission, to continue to develop our role as the leading international information, support and scientific research charity for nystagmus is supported by a number of key aims:

- Ensuring the physical effect and social impact of nystagmus is at the heart of everything we do
- Continually developing and improving the quality of member services
- Increasing the awareness of nystagmus and the support and treatment available
- Providing encouragement to members, sufferers and their families
- Organising events for professionals, members and others which provide support and promote our aims
- Using conferences, exhibitions, workshops and seminars to promote both nystagmus and the Nystagmus Network
- Providing a focal point for both gathering and sharing information on nystagmus and its effect and impact
- Developing, publishing and distributing practical, specific and scientific information about nystagmus

- Using our funds to further the cause of our members, people and families with nystagmus and scientific research into the causes, treatment and ultimately cure of nystagmus
- Lobbying for proper support in school for children who have nystagmus

Our objectives for the five years reflect our mission by updating and improving the information we provide; finding new and effective ways of reaching and supporting people and families with nystagmus and promoting and funding research into nystagmus. We will report back in future years on progress with these objectives.

We are beginning to appreciate the impact our first international scientific workshop has had on what is now a fast moving and exciting world of research on nystagmus and related fields. The second workshop is now well into the planning stages and support from the scientific and academic communities

## Committee changes

Three committee members have stepped back during 2007: **Gill Taylor** (Secretary and Netletter editor), **Chris Abberley** (Fundraising) and **Andrew Brechin** (Webmaster).

We thank them for their contribution in the role they played and to the committee itself and hope they will be able to rejoin us when personal commitments allow.

Equally we welcome two new committee members. **Kathy Williams** has taken on the role of Netletter editor and is gradually introducing members of the committee to the membership through a series of thumbnail sketches. Also **Chris Green** is providing invaluable marketing and management advice and making links with potential contributors of one-off services.

Our committee continues to work extremely hard in their individual roles as well as contributing to strategy and decision making. Thanks go to

**Claire Entwistle** (Database and Membership)  
**Jo-Anne Winston** (Shop and New Membership)  
**Katy Faulkner** (Governance and Direct Debit)  
**Pam Jarman** (link with the RNIB)  
**Andy Machin** (Printing and Distribution)  
**Carol Bashford** (International Workshop)  
**Vivien Jones** (President)  
**John Sanders** (Vice President)  
**James Taylor** (Website)  
**Peter Leon** (Treasurer and Accounts).

Our Information and Development Manager, **Paul White**, has been key to the preparation of the Strategic Development Plan; development of links with new partners; organising our Open Day and ensuring support and information for Members and others wanting to know more about Nystagmus.

Finally a special thanks to the families of our committee who sacrifice their time with its members to make the vital contributions which make NN work and progress.

**Tim Horsley, honorary chairman**

# Information and Development Manager's (IDM) report

## Enquiries

At more than 650, the number of enquiries by email, telephone and letter in 2007 was similar to 2006. In addition, the Nystagmus Network website forum saw an increase in activity. Here people can ask questions and receive answers not just from myself and NN committee members, but also from other people with nystagmus who have similar concerns and experiences.

## Quotes from the website forum:

“ I am very grateful to have found this site because there is wonderful information - thank you so much for providing this. ”

“ I gained 3 A levels, went to university, achieved a first degree honours in English literature, went on to get a PGCE and found a fantastic job at a brilliant high school. After only a year, I was promoted to management. Your website is great, particularly the forum. It's so important to offer a community isn't it! I just felt compelled to be yet another person to let you know that this condition has not changed my life in any negative way. ”

If you have access to our website, please have a look at the forum and add to it as you wish

[www.nystagmusnet.org](http://www.nystagmusnet.org)

## Practical Help

As in previous years we received numerous enquiries about Disabled Living Allowance (DLA) awards, and support for children with nystagmus in school. With the help of NBCS (National Blind Children's Society), Action for Blind People and

other organisations, most if not all the people who contacted us about these issues had successful outcomes from their enquiries.

## Events in 2007

In November 2007, NN's chairman Tim Horsley, vision scientist Debbie Wiggins, Chris Green (a committee member and parent), his wife Louise and myself organised a training event in Birmingham. We talked about NN and nystagmus to a group of QTVI (Qualified Teachers of Visually Impaired Children) from Nottingham. Our hosts for the day were Action for Blind People, Birmingham.

We exhibited in Leeds at the annual REVEAL exhibition in March, and in May

I took the NN banner and information to the Sound-Site event in Glasgow. This exhibition was as busy and enjoyable as in previous years and, as an added bonus, I visited the headquarters of the 7th Coatbridge Boys' Brigade Company where I was presented with a donation for £1500 in recognition of the support that NN gives its members.

We also exhibited in July at Sight Village in Birmingham -- the largest annual exhibition in the UK of equipment and services for people with a visual impairment. We also attended the Nottingham RNIB Low Vision Awareness Day in September.

## Fund raising and donations

NN received many donations during the year. Some came from people who donate regularly. Others were in lieu of receiving presents on special occasions such as wedding anniversaries or instead

of sending Christmas cards. We also received donations from Sutton Coldfield Rotary Club, from legacies and from national events such as "Jeans for Genes day."

## Stockholm marathon runners

During 2007, we saw a large increase in income from sponsored events. NN members and others made great efforts to raise money on our behalf. For example, children walked for us in Scotland, cyclists pedalled from London to Brighton and London to Paris. Runners toiled through the West Midlands, Reading and even Stockholm in order to support the work we do. We are grateful to all of them.

## Open Day 2007

The 2007 Open Day, entitled "One Vision", saw the first joint planning event by Nystagmus Network and the Albinism Fellowship, with input from LOOK (The

National Federation of Families with Visually Impaired Children) and NBCS (The National Blind Children's Society). The venue, for the third year running was Queen Alexandra College in Harborne, Birmingham. As before, we were made very welcome by the college management and staff.

A major difference in 2007 was the presence of an enormous marquee in the college grounds where LOOK staged "Talent in the Tent" a showcase for young people to demonstrate that nystagmus doesn't stop you having talent. The programme for adults was also different with themed discussions groups replacing formal information sessions. These were led by Debbie Wiggins from Cardiff University, Clive Matthews from NBCS, Dawn Hartgen, an independent adviser on state benefits, and Vivien Jones, our honorary president.



Stockholm marathon runners

## A quote from the forum

“ We all went to the NN open day and it was brilliant as well as an emotional roller coaster. Just talking to people who understood the condition and seeing other children with N was both strange and reassuring in a funny kind of way as it's not something you see on a regular basis! I have to say we learned more in 6 hours than we have in the last 9 months. ”

## Joint working

The Albinism Fellowship and NN shared the same space at Sight Village in Birmingham. The arrangement benefited both organisations as

nystagmus and albinism often have common features and effects on vision. Our intention is to be side by side at the July 2008 Sight Village exhibition.

As you will learn from other parts of this report we have been very busy during 2007 planning for the future and what we aim to achieve in the next 5 years. I am grateful for the help and support I have received in my work from committee members during 2007 and look forward to working in the coming year to achieve the aims of our unique service for people with nystagmus.

**Paul White,**  
**information and development manager**



NN Open Day 2007, QAC Birmingham

# Research report

Gene therapy, drugs and surgery. We talk about all three so easily now as promising areas of nystagmus research. Yet in the 1980s in the early days of the Nystagmus Network, surgery was the only game in town and its main if not only purpose was cosmetic – to correct a head turn. The US is almost certainly leading the way on surgery.

Here in the UK the focus is on drug and genetic research, although centres around the world -- in Australia, France, Greece, India and Switzerland for example – are contributing too. International co-operation is particularly useful on the genetics side, where pooling data from a few large families with nystagmus can really speed up progress.

In 2007, NN paid an initial £5,000 of a £10,000 grant to fund genetic research by Southampton University. That's a lot of money for a charity with annual income of just over £50,000. So why did we choose genetics? Because in 2006 an international group led by Leicester University discovered the first nystagmus gene (**FRMD7**). Linking that gene to nystagmus is a major step forward. Now the goal is to find out exactly what **FRMD7** does to cause nystagmus.

## Progress with pills

In Leicester, as well as working on genetics and other nystagmus projects, researchers are pushing ahead with efforts to find a drug therapy. A pilot project has produced encouraging results, so Professor Irene Gottlob and her team now want to conduct a larger trial.

NN has provided funding for this work in the past and plays an important role in recruiting research subjects too, as Professor Gottlob explains: "I couldn't do it

without them. A lot of people come from the NN web-page. It is extremely important. So I would really like to thank all the volunteers who have participated in our studies – genetics, pharmacological, prevalence, etcetera."

## Global influence

In addition to our support for individual projects and centres in the UK, we are also helping to set the long term agenda for nystagmus research at the global level. The 2009 research workshop, for example, will bring together experts from Australia, Germany, Italy, the Netherlands, Slovenia, the UK and the US.

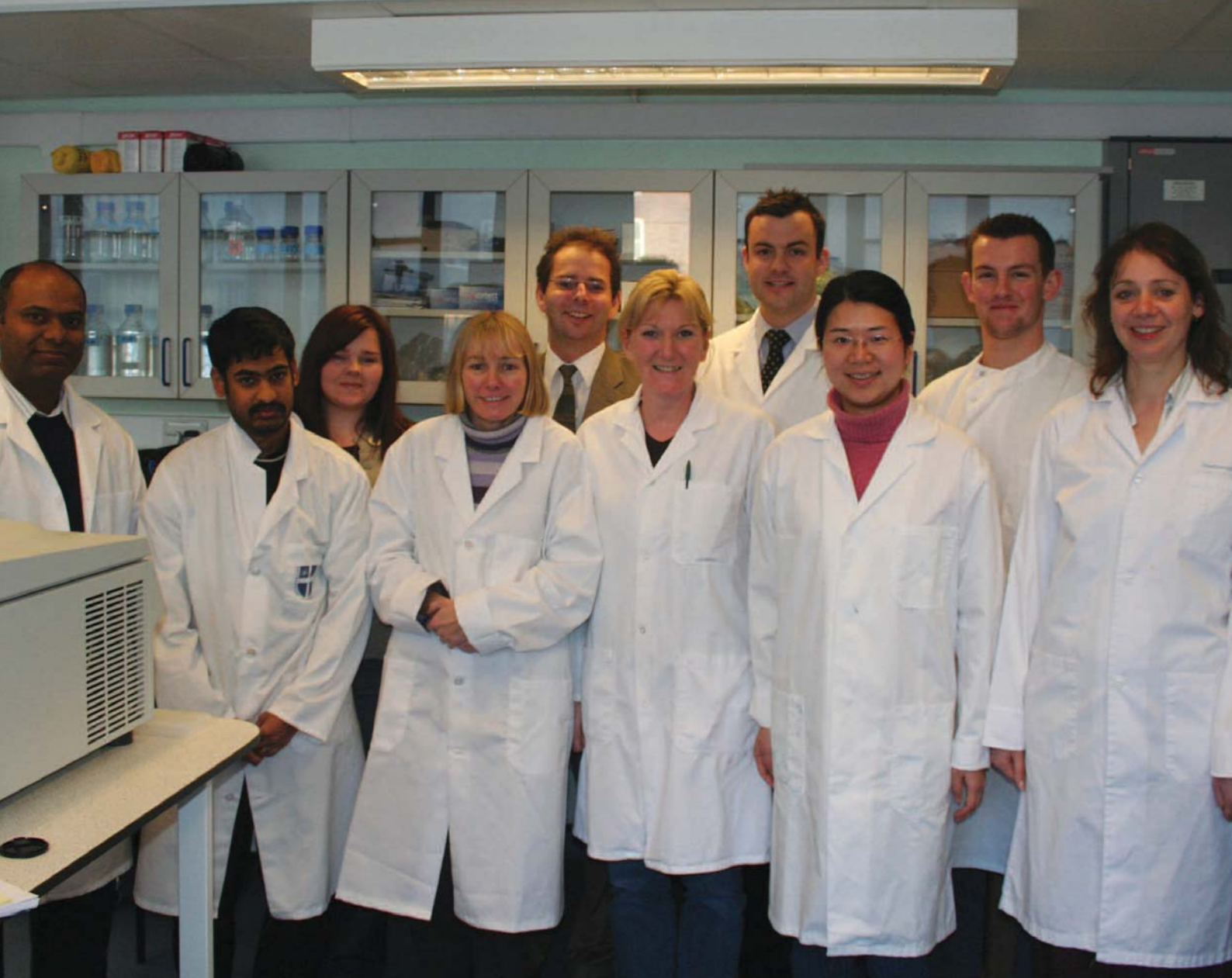
## PhD

Cardiff University vision scientist Debbie Wiggins ended 2007 by passing her PhD on nystagmus and stress. Why is one PhD so important? Well, for several reasons. Debbie passed with flying colours, which is all the more impressive since she has nystagmus herself. Secondly, her work has already been published. Thirdly, NN part financed her studies, showing once again how a support group can contribute to progress in research.

Cardiff now has another nystagmus research student, Phil Jones, funded this time by the College of Optometrists. So NN is getting a good return on its initial investment.

## New thinking

Those are just a few of the highlights of 2007. Many other centres and individuals are chipping away at the mysteries of nystagmus, looking at why it occurs, how and what people with nystagmus see and of course what can we do to treat or cure it.



### Southampton genetics research team

In Plymouth, Professor Chris Harris has come up with a possible new way of categorising nystagmus. If his hypothesis is correct, it could have important consequences for how we think about nystagmus. The Institute of Child Health in London, with other centres, is also studying different ways of modelling nystagmus so that we can better understand what goes wrong and why.

In Manchester, researchers are considering the effects of nystagmus on hand-eye coordination. Their findings may shed some light, for example, on why so many people with nystagmus struggle to play ball

games. Separately, a research project on nystagmus and posture conducted in Swansea, is now complete and its results will be published during 2008.

All this research is very exciting and encouraging. However, some very serious gaps remain in our approach to nystagmus. For instance, at the basic level of how doctors treat patients with nystagmus, we still have no standards. So developing clinical standards for examining patients with nystagmus must be on our agenda for the future. In the short term, such a simple step would make a very big difference.

**John Sanders, honorary vice president**

# Treasurer's report

A glance at the accounts printed in this Report will show you that we had a surplus in 2007 of nearly £20,000. There are positive and negatives reasons for this. On the positive side our subscriptions rose slightly over 2006, but more importantly donations and fundraising rose from £22,000 in 2006 to £28,500 in 2007.

Unlike the figure obtained in 2006 (one large donation of £10,000), the 2007 amount was raised by members through a series of personal giving and fundraising events. Our thanks go to the many people who contributed.

Contributions for fundraising have been boosted by our membership of Just Giving. This web site offers an easy path to both organising and contributing to fundraising. Check out our web site for the latest endeavours.

Negatively the book on nystagmus research, originating from our 2005 Workshop is not to be. This money has therefore not been spent. The new Early Onset Nystagmus which has been promised for 2 years has also not yet materialised. We are however

ever hopeful. We have been promised that publication (and therefore costs) will happen in 2008.

## Watchful eyes

The committee keeps a careful eye on expenditure. We do not waste your money. In this regard general office expenditure is about £600 lower than in 2006. Open Day, the expenditure of which is always subsidised for members, had a net expenditure of £900 (£1,100 in 2006). In spite of general price rises this was mainly due to combining Open Day with other interested organisations.

Printing costs have risen as can be seen from our expenditure on leaflets and the newsletter etc., but we hope that members appreciate the new layout and professional design of Focus and indeed this report.

In conclusion, our finances are in a healthy state thanks to our members' support. However, we have ambitious plans – including the 2009 research workshop – so please continue to give that support.

**Peter Leon, honorary treasurer**

# Financial Accounts 2007

	2006		2007	
	£	£	£	£
<b>INCOME</b>				
Grants				
Subscriptions	10,595		11,078	
Donations	22,010		28,514	
Wobbly Eyes + Leaflets	368		339	
C Harris Book	938		1,350	
Xmas Cards	1,395		2,047	
Northwick	512		814	
Northwick Cards	33		47	
Teachers Pack	1,080		1,094	
Other Information	0		0	
Interest	2,911		4,064	
Open Day	386		2,730	
Other	11,729		1,292	
	<b>51,955</b>		<b>53,368</b>	
<b>EXPENDITURE</b>				
Office	19,625		18,959	
Committee	737		541	
AGM & Newsletter	4,257		4,802	
Leaflets	524		1,188	
Wobbly Eyes	0		0	
C Harris Book	707		0	
Xmas Cards	904		1,746	
Northwick	62		2,553	
Northwick Cards	0		9	
Open Day	1,520		3,607	
Other	10,050		20	
	<b>38,384</b>		<b>33,424</b>	
<b>Net Income/Expenditure</b>	<b>13,571</b>		<b>19,943</b>	
Research and Workshop				
Workshop income	0	0	0	0
Research expenditure	0		5,000	
Workshop expenditure	467	467	0	5,000
<b>Special Income/Expenditure</b>	<b>(467)</b>		<b>(5,000)</b>	
<b>Special Income</b>	<b>0</b>		<b>0</b>	
<b>Total Income/Expenditure</b>	<b>13,104</b>		<b>14,943</b>	
<b>Cash at the Bank 31st December</b>	<b>87,731</b>		<b>102,674</b>	

Accounts prepared by  
Peter Leon - Treasurer  
Accounts certified by  
Andrew Black ACA

 ARBlack

Date 18/02/2008

Date 13/02/2008

Nystagmus is a form of visual impairment, which cannot be corrected by glasses or contact lenses.

The Nystagmus Network support group promotes awareness of nystagmus and encourages research into this complex eye condition.

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