

# Hypoparathyroidism UK

The UK's first HPTH website & forum

Newsletter no.2

Registered members 218

Forum members: 196

June 2007

This newsletter aims to keep you informed about the work of HPTH UK and it's campaign to raise awareness about Hypoparathyroidism , to bring you updates on any news, medication, research, relevant articles and case histories to help you manage your own Hypoparathyroidism.

## HPTH UK

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## Medical Advisors

**Professor William Fraser**

**Dr Peter Swift**  
**Dr Simon Pearce**  
**Dr Petros Perros**  
**Dr Denise Adams**  
**Dr Stephen Bellamy**  
**Dr Jeremy Allgrove**

## URGENT NEWS!!!

\*\*\*\*\* NEW UK CAMPAIGN TO DEVELOP HPTH GUIDELINES \*\*\*\*\*

**This newsletter is to tell you about something that concerns all of you and to ask for your help. HPTH UK have set up a project which we hope will improve the treatment of HPTH patients, bring greater recognition of the condition and standardize care throughout the UK.**

In our first newsletter, last September, you may remember that, as part of our campaign on HPTH treatments, we hoped to set up a special interest group to develop national guidelines on the treatment of Hypoparathyroidism for the use of health care professionals. Today, I am delighted to tell you that such a group has now been formed. Some of the country's top professors, consultants and GP's have expressed their interest in the project, recognized a need and, without any hesitation, have all kindly agreed to give us their time and expertise. They will be coming together to review current treatments and research, taking on board your views as members of HPTH UK, and pooling their own collective knowledge to develop the first published UK treatment guidelines for Hypoparathyroidism and related parathyroid conditions.

### **This will be a huge step forward for us all!**

- Doctors will have guidance on the treatment and management of HPTH for the first time – this alone will change patients' experience at diagnosis, crisis admission etc.
- Raising the profile of HPTH throughout the UK in this way will make it a more recognised medical condition - we will no longer be misunderstood or misdiagnosed.
- The need for regular monitoring and home testers will become more evident – as will the need for licensing treatments such as PTH for our specific use.
- As an officially recognized condition with its own charity, health authorities & companies will be more prepared to develop resources and services for us and we will have easier access to funding, licensing and new initiatives.

### **BUT - to do this we need your help.**

**If HPTH UK has helped you, if you want better treatment to be available to you and other HPTH patients, if you would like to be part of this campaign to put Hypoparathyroidism on the medical map there are two ways to help. Please – read on.**

# 1) FUNDRAISING

**The total costs involved in setting up this project are £10,000. So far donations to HPTH UK total £1,150 so we have a very long way to go!**

New regulations from the Charity Commission mean that while we are affiliated to the USA Hypoparathyroidism Association, a registered charity, we legally have to become a separate UK charity in our own right. We can't be officially registered until we have an income of £5000 – or the promise of £5000 – which means that initially it may be difficult to get companies to sponsor us. However, we have to start somewhere! Innervate, the company who will be running the campaign for us ( setting up the conference for us, getting the guidelines written up and published etc) will be approaching large companies on our behalf and GE ( previously Abbott) have already kindly started us off with £1000. Thank you, Ian Yeeles at GE.

**We really need help from all of you to get Hypoparathyroidism on the medical map so please - do what you can, however small.**

**This is one idea we are asking you all to take part in:**

## Raise Funds For Free If You Shop Online

**We've found an easy way for you to raise funds for HPTH UK and save yourself money - simply by shopping online!**

We've teamed up with **easyfundraising**, an online shopping directory listing over 400 of your favourite stores, including **Amazon, NEXT, Debenhams, John Lewis, M&S, Tesco, DELL** and many more. Every time you shop online with any one of them, we'll receive up to 15% of every purchase – at no extra cost to you!

It's completely **FREE** to register and use and it doesn't cost a penny extra to shop and raise funds in this way. In fact, you can even **SAVE MONEY** as many retailers give exclusive discounts, special offers and even 'e-vouchers' when you shop through the easyfundraising site.

All you need to do is log on to our web page at <http://www.easyfundraising.org.uk/hpth> - then complete the free registration and click on the link of the store you want to visit for guilt free shopping!

What's more, if you **register before 15 July 2007** you could win **£250 Amazon vouchers**.

*Ask your friends to join or add this signature to your emails and ask your friends to do the same: Support Hypoparathyroidism (HPTH) UK for free when shopping online with over 400 brand-name retailers including; Amazon, NEXT, M&S, John Lewis, Debenhams, HMV, The Body Shop, Vodafone, DELL, Woolworths, PLAY.com, Interflora and Comet amongst many others...*

[www.easyfundraising.org.uk/hpth](http://www.easyfundraising.org.uk/hpth)

**Every penny you raise will help us to get UK guidelines on the treatment of Hypoparathyroidism developed and published so if you shop online anyway, you've nothing to lose!**

See next page for further individual and company fundraising ideas.....

## Individual fundraising ideas

- Donate some money yourself: **HPTH UK sort code:09-06-66 Account no: 42582811**
- Hold a small coffee morning/tea party/ cheese and wine evening/ picnic/BBQ. Guests pay at the door and/or pay for their drinks, food etc. Or more simply, start a coffee chain - invite 4 or 5 friends round to buy a few drinks/cups of tea/coffee and then ask each one to do the same at their own houses. It soon adds up!
- Think about the skills you have to offer. Cook some friends a meal and charge restaurant prices!
- Hold a raffle. Be brave and ring/ask in your local shops for prizes – you'll be surprised at the positive responses! Sell cloakroom tickets at 5 for £1. (An authorisation letter is available from HPTH UK on request or just take along this newsletter to show that we exist.)
- Get sponsored! Got a good idea? Get a sponsor form from us.
- Write a letter to your bank, your supermarket, your local firms and ask for a donation.
- Email us for a home collecting box and save your loose change.
- Hold a horse race party ( record a few horse races on tape) or a camel race party ( buy DVD on ebay for £4.99) and have a hilarious day. A BBQ and a few small prizes would add to the fun. See [www.ectodermaldysplasia.org/text/xamelrace.htm](http://www.ectodermaldysplasia.org/text/xamelrace.htm) for an account.
- Piggyback fundraising – no, not another race but a way of reaching a wider audience. As we are such a small group it's a good idea to join in with larger fundraising event such as a school fair, hospital or local event. Many events have tables to hire where you can set up your raffle, plant/cake/tombola stall or sideshow. ( A4 Information leaflets about HPTH UK for display at such events are available)

## Company or group fundraising ideas

- Ask your company to choose us as their Charity of the Year.
- Name a day for fundraising activities and get each department to compete
- Hold a large event. While schools often need to fundraise for themselves, some choose a charity to support. Events such as a Quiz night, a ball night or disco are always popular.
- Hold an auction of promises. A great way to raise money where people bid for services offered by others – from an hour's gardening or baking a cake to those involving specific skills such as accountancy, will writing, a haircut, a photo session, a ticket to a concert etc. The more variety and range the better. We could also hold a members online auction of promises – if you have anything to offer PLEASE send in your promise.
- Donate shares to us through <http://www.sharegift.org>. ShareGift is an easy and convenient way for shareholders to donate unwanted shares to charities and get rid of the nuisance of a small holding and its attendant paperwork. Companies also benefit, by reducing the costs of shareholder communications. We do not charge companies, their shareholders or charities to use ShareGift.

If you have any ideas, questions or useful contacts please let us know

**THANK YOU**

## 2) Send in your views

The second way to contribute is by taking part in the decision making process and sending in your ideas and suggestions on the following:

### a) Guidelines project

I want to make sure that everybody is able to contribute to this project so that the guidelines are really representative of your views and needs. If you have any thoughts on particular subjects you feel should be included, I'd very much like to hear from you. I will be representing you on the day so please make sure I have your comments and I will make sure they are put forward.

You can email them to me at [liz@hpth.org.uk](mailto:liz@hpth.org.uk) or add them to the **Guidelines suggestions** topic on the forum

### b) PLEASE add your details

to the forum topics '**Tests & Medication - add your data only here**' and '**Symptoms in the 'normal' range? Add yours**' so that we can collect some useful data to show the doctors what really goes on. You can also **add your story** and help someone new to HPTH. If you haven't yet registered for the forum go to <http://www.hypoparathyroidism.org.uk/board/policy.asp>

### c) Members only pages

The new website will have Members Only pages. As part of the drive to raise funds, I am considering asking for a one off membership payment of £15 on joining HPTH UK. This would give access, by password to the forum and members pages which would hold newsletters, patient info leaflets, etc. Current members would not be expected to pay. We felt strongly about keeping HPTH UK a free resource but having been directed to websites of other rare diseases we do seem to be unusual in this. It would help us with running costs – HPTH UK is run voluntarily. We'd like to know what you think, please. It's your site. Would you have joined if you'd had to pay? If so, do you think a one off payment is a good idea or would £5 annually be better so that membership can be regularly updated?

Please let us know again by email [liz@hpth.org.uk](mailto:liz@hpth.org.uk) or on the forum on the **Members Only Pages** topic.

### Missed the first newsletter?

For those of you who missed our first newsletter last year and would like to catch up, here is the link:

<http://www.hypoparathyroidism.org.uk/hpthuknewsletter.html>

You may particularly like to download the '**Letter for your GP**' written by Liz Glenister and approved by Dr Adams who herself had HPTH. This was designed to help you discuss with your GP ways in which you could manage your HPTH together and should be used in conjunction with Dr Adams' own letter that you will find on the website on the Articles page.

## CAMPAIGN UPDATES

### Raising awareness

#### Hypoparathyroidism Awareness Day

Thank you so very much to Peter, Anna and Freda, the three members who so generously sent us our very first donations to mark the Day. They will have a special place in the annals of HPTH UK history! Hopefully these gifts will be the first of many. Thanks to all those who put up a poster and to those keen-eyed members who spotted the spelling mistake! Sorry there wasn't a prize! We had a surprising amount of interest from health centres around the country who wanted to find out more and who put up displays about HPTH and circulated posters. Although this was a necessarily small beginning it has, at least, put us on the Department of Health map and we hope to plan greater things for the next one. It would be better to change the date to a time of year when more people can get out and about and I am going to suggest this to the other world groups. Any suggestions?

#### Treatments

No further news on home testers or the new full Parathyroid hormone (1-84 Preotact) here yet but we will keep you posted. The Guidelines campaign has been specifically designed to address both these issues so the more we can fundraise to get that off the ground the sooner we will get results.

# MEMBERS' STORIES

**Each newsletter will publish a selection of stories from HPTH UK members. Telling your story and knowing it is being heard is now recognized to be an important part of the healing process in chronic illness. It also helps the reader who may be going through similar experiences and seeking information or reassurance. The bravery and perseverance of the people in these stories are deeply moving and give us strength to carry on when faced with difficulties. I think they give hope and deepen the respect we have for each other and the way we cope. The stories themselves should not be seen as negative or depressing but be as a means of strengthening our determination to campaign even harder for better treatment.**

**These stories are reproduced here by permission of their authors. If you would like your story to be included in the next newsletter, please send it in, marked 'newsletter'.**

## 35 years to get a diagnosis

I had an emergency Tracheotomy due to having my appendix taken out in 1959, this was probably the cause as the surgeon had not done a Tracheotomy in twenty years. Since 1963, I was having what I thought was a fit and so I hid this from my parents. My father told me to stop when he saw me having one, for many years I carried on with my life but when I exerted myself, I found that the fits getting worse.

When my wife saw me having one that she contacted my GP to make an appointment, this was in 1994 when it was first diagnosed that I had Hypoparathyroidism. They could not get the dosage right, therefore my calcium rose too quickly from 1.33-2.97. Then in 1996 I was referred to the renal unit where they found calcium deposits in my kidneys and I was diagnosed with early stages of kidney failure. They found that my calcium was too low at 1.3 so they started treatment with alphacalcidol and soluble calcium tablets. They tried different dosages till they found the right dose, my blood calcium is now stable at the lower end of the scale 2.0, my creatinine levels are stable at 594, but they said that I will need dialysis by 2009.

In the interim period I was referred to a neurologist who thought I had had a stroke. I was then sent for a ct scan to see how much oxygen was getting to my brain but when the results were recieved they found I had calcium deposits on the brain.

Derek , Portsmouth

## Pregnancy, breastfeeding and HPTH

Hypoparathyroid following surgery for Thyroid Cancer in April 2002. Moved from London to Dublin May 2005.

I'm lucky that I'm pretty stable with my HPTH, and only had crashes when I was first diagnosed in 2002 following surgery fro Thyroid Cancer. I do get pins and needles every day, but I've got used to it , and minor cramps but if I move about I can usually get rid of them, and then I usually remember that I've forgotten a Sandocal. I@m currently taking Sandocal 400 ( two twice a day) and Alfacalcidol (Alpha D) (1mcg six days a week and 2mcg once a week.)

My husband and I had a baby daughter in July 2004 and I had excellent care in pregnancy with a woman obstetrician at West Middlesex Hospital in Isleworth who takes a special interest in endocrinology in pregnancy. I had blood tests every 3-4 weeks to check my levels, which were quite stable good actually. I had to increase to 6 Sandocal a day, but no other major problems with the pregnancy. The doctor even pre prescribed IV Calcium if it needed to be administered if I had continual vomiting in labour which would call my levels to crash.

I was breastfeeding for 1 year after Roisin was born at the higher Sandocal levels, without problems and 2 months ago (2 months after ceasing breastfeeding) I was put back down to 3 a day. The first week from 6 to 3 was not nice, (more cramps and pins and needles than normal) but I stabilised then, and I'm back to my pre pregnancy levels now.

There has been no proper research done on Alfacalcidol whilst breastfeeding. There was a worry that the baby might become Hypercalaemic, as studies showed in rates that it can transfer through into breastmilk, but 2 weeks after I started feeding Roisin she had a blood test which showed her calcium levels to be normal, so I'm proof that it is possible. None of the medical staff had come across a breastfeeding woman on Alfacalcidol before, and I was a

guinea pig, but I was adamant I wanted to feed her myself. Now there is some data to spread around!

I'd love in the future If I could cease taking the Sandocal as it is such a pain to dissolve and I'm always leaving it dissolving and then forget to take it and come back to a glass with solidified calcium up the glass! Also it is awkward when travelling and when you're out and about.

I am now pregnant for the second time and having monthly blood tests instead of 6 monthly during any pregnancy. On my last pregnancy I found there was very little research done into Pregnancy and breastfeeding with HPTH and so we had to make up the rules as we went along. If there is ever any survey about Pregnancy with HPTH I would be a willing participant!

Blaithin, Dublin

### **Congratulations Blaithin!**

Recent research links:

**Maternal calcium and skeletal homeostasis during pregnancy and lactation  
Chapter 3 - Urszula S. Masiukiewicz, M.D., and Karl L. Insogna, M.D.**

June 30, 2003

<http://www.endotext.com/pregnancy/pregnancy3/pregnancyframe3.htm>

## **Hyperparathyroidism**

Hi all, I have never used a forum before so am just finding my way I have been reading all your messages for a while and have finally plucked up the courage to join in.

This site is just so refreshing, I have never been able to find anyone who had even heard of my problem. I was diagnosed with Hyperparathyroidism at 18 (now 41!) Had two ops on my neck, and all my parathyroids and thyroid removed. I then had Hypoparathyroidism. It was when, after this that my levels were still high they then found the one behind my chest bone which I have just had removed for the third time!! (it keeps growing back!) . I feel like I have been on a roller coaster for quite some time now, especially after having the thing removed my levels have been all over the place. I now take sandocal and one alpha. The last year has been a nightmare, I have just felt so ill and so depressed and plus the fact that I have a three (then 2 year) old. Also I wasn't well when he was born. Calcium was 3.03 whilst giving birth, then not well for ages after. My last procedure was June this year and it is only in the last two months I have finally got back to normal, to get my levels balanced, I feel so fantastic it is amazing.

It is such a relief to find you all as I really felt I was so alone. I find it so hard to describe how I have been feeling, even to Doctors, you begin to feel that you really must be making it up. On really bad days I have only been able to manage very minimal movement, and yet just two weeks ago I played a game of football on the beach with my son and his two cousins!! A moving occasion in more ways than one! I just hope I can maintain my levels to feel this good as I really had forgotten what it was like to lead a normal life. And fingers crossed it doesn't grow back again!!!

I have always longed to have an illness which there is a leaflet about, some thing you see at the surgery etc!! So this site really is just so refreshing, there is just no info out there. Fantastic!!\_Sandocal when I took them I had to spread them out, plus I am sure that as each ones effect ran out I would start to feel low, or when I had just taken it the effect of high . It drove me mad the constant up and down, felt dreadful. However I have finally weaned my self off them and am trying to balance with Alfacalcidol only and feeling much, much better for it. I have learned to love Sandocal now (as Liz said I would!!) as I only use it if I think I am low and it sorts me out, which is now very rarely. I get very tingly too when low. When high I get very dizzy and my vision is blurred and I have a very dry mouth and a thirst that I cannot quench.

I was also going to say that even though your levels may be high they may have dropped from the high they were and now you are getting the effects of it being low (even though its not actually as far as normal goes), just low for you though so your body react to a drop!!! Did any of that make sense!! My concentration does not seem to have returned!!

Also wanted to say the week before my periods my calcium definitely drops and for the whole week I end up taking Sandocal to help me function! After some Sandocal and a bit of a rest I am feeling much better now!

Pat, Warwickshire

## Pseudopseudohypoparathyroidism

Life with an illness I never knew I had!

Ok, so since having my diagnosis what seems weeks ago, when in actual fact it is only something like three weeks I think. This has all been a bit of a shock, but I have been doing one heck of a lot of reflection....

So as a baby, I was always, "bigger" or stockier I think the word is, than my brother and this is one thing that is clearly noticeable now, I was smaller in height, but build...! I slept a lot and would always be irritable. Apparently my Mum and Dad told me that once they were really worried about me sleeping too much so they took me to the doctors about but they just said I was healthy so everything was ok. That's all I know really about being a baby, but things start to be in my memory as my memories when I started to go to nursery. The height was a thing, as I am slightly smaller than all of the members of my family, but yet I am stockier. This resulted in me being teased about my height even at that age! As a child my moods were terrible apparently and this is one thing that I still suffer with and I am finding it hard to deal with!

At middle school I got teased for being a big girl which later developed into bullying on a severe level. The development of my body happened very rapidly at school, as I developed in every sense very quickly. Some of this growth did not happen equally, and as a result I had a Breast Reduction on one side. My periods were totally erratic and resulted in me having terrible migraines and being sick a lot and very thirsty. As a result of these bouts I was put on The Pill. I had about a year of finding one that suits me and now I'm on Cilest till I wish to have children. During my later years at school I had weight problems and emotional problems which I still do at uni now, but thanks to the learning contract this should be eased a little now.

At university I struggled with tiredness a lot during both my 1st and 2nd years, but just put that down to being away from home and a bit of a busy social life! I was also diagnosed with asthma. My third year at uni was my placement year. It was this year that many things became highlighted about my condition. Due to me being put under a lot of stress a lot of symptoms started to show similar to IBS, so my Mum took me to see a consultant. I had a transition study and a colonoscopy. This wasn't pleasant, but did help lose 2.5 lbs! I also had several blood tests, this meant that my Calcium level was checked and this came back as being low. I was then referred to Dr Paul Belchetz, who within about ten minutes of being in his room had preliminarily diagnosed Pseudopseudohypoparathyroidism. He ran several tests on me and then said yes its Pseudopseudohypoparathyroidism. The original symptoms are now slowly stopping as they are things to do with my Calcium level.

I struggle with the change in temperature and can get very cold even on hot days. I also find that I ache badly a lot, even the slightest of walks can knock me around. I get very tired and have to sleep and can often fall asleep at the drop of a hat! My moods are the main thing that is hard to deal with.

I started on 1 2.5g Calcichew forte tablet a day, for my Pseudopseudohypoparathyroidism. Recently my symptoms got worse. I don't know if this is due to uni, but I needed help to get me 😞 instead of being 😊 and 🌈 like i used to be. My GP didn't fully understand my condition so I took advice from the HPTH UK specialist Dr Swift and we tried a one month trial. Now I can say that the new meds, Calceos by Provalis, are great! I don't get as many "low" points during the day now, not as many aches or pains, head is definitely "with it" as i have taken up the keyboard/piano. It is helping me relax a lot at present, which is needed. My calcium is up - woo hoo! I am now at a level of 2.35. so it looks like the new meds must be doing something. My thyroid is functioning normally too. So that's me.....!

Sarah, West Yorkshire

**Sarah has just finished university and been offered job in Exeter which she has accepted.  
Good luck Sarah and well done from us all!**

## Hypoparathyroidism

Full Thyroidectomy and removal of one parathyroid adenoma plus another half a parathyroid which was adhered to the thyroid 08.06.2005 in Los Angeles. Returned to UK September 2006

My GP told me she has no idea about my thyroid and parathyroid problems as they are beyond her knowledge (fair enough)so referred me to the Hospital Consultant. He was very pleasant but not really interested, he did not look at any of my reports which I had brought with me from my American Doctor (I have recently returned from a two year RAF tour in Los Angeles), he only told me that I do not need magnesium as I get all I need from my food!! He also told me to do bloods 3 monthly, no mention of no cuff, and to see him again only if TSH and Calcium levels not stable. Just had results and no they are not stable but GP says I'm O.K. I'm not. I hurt all over and I am actually rather frightened. Frightened of being left only to find out much later that I have problems that can no

longer be fixed but could have been if someone had bothered earlier on in my blood instabilities. Basically the consultant was useless.

However, he told me he would refer me to the surgeon (I had complained that I felt like I have a lump in my throat and my throat is very tight) as she has her own ultrasound machine and that route would be far quicker than waiting for the normal route. Anyway my appointment with the surgeon finally arrived. I was expecting to be given a cursory acknowledgement and then scanned, instead a somewhat elegant lady extended her hand and introduced herself. She asked me to tell her my story and said that she would like to look at my American medical history. She informed me that I was her last patient of the morning so time was not a problem! I was with her for almost one hour. I never did get an ultrasound scan but she informed me that in her opinion I clearly have Hypoparathyroidism and asked what meds I take. I showed her my Thyroxine, my Adcal and my magnesium. The thyroxine is fine, the magnesium is debatable and she tutted at the Adcal. She told me that she would like to put me on relatively huge amounts of vitamin D which may make me feel awful until the amount I require is found and I will have to have blood tests every other day.

I received a copy of the letter that the surgeon wrote to my GP stating that I am to be started on 1 mcg daily of One-Alpha and to have blood tests twice a week - a bit of a relief there. She also arranged for me to have a barium swallow to check that there is nothing wrong with my throat, she thinks it is probably scar tissue that is still a bit tight and , in fact, the results were clear. She told me that if I needed to see her at all she would be happy to see me and she has repeated that in her letter to my GP. All in all I'm feeling a bit pleased with myself for being so fortunate to be referred to "the surgeon".

My GP seemed to want me to deal with my illness, as much as I can, by myself since I know more about it than she does. When I offered to give her the information I did have she did not want to know. I have changed my GP to someone else in the same practice, the new one is more aware but he seemed to think my calcium levels were normal. He was able to answer some questions I had so I will stick with him for the time being.

I am now on One-Alpha tablets and feeling a bit better. I had blood tests twice a week for two weeks, I am currently on bloods once a week for a month then I go once every two weeks for a month and then monthly. I did not have a rough time although I did have a fair amount of pain for 4 days when I first started taking the medicine that has now gone. I dealt with the pain by telling myself I had pain on the way down so it is only reasonable that I should get it on the way back up too. I may well have been talking nonsense to myself but it helped.

Incidentally, I seem to have suddenly developed lots of dental caries and must go to the dentist as I am starting to get some discomfort, is this common? Do dentists understand about Hypoparathyroidism? I have also had several changes to my eye prescription in the last two years and must see an optician.

Thank you for being there. If there is anything I can help with.....

Gillian, Gloucester

**IF YOU WOULD BE INTERESTED IN HELPING TO RUN HPTH UK OR HAVE ANY SKILLS OR ADVICE TO OFFER, PLEASE GET IN TOUCH. WE'D LOVE TO HEAR FROM YOU.**

**WE ARE AWARE THAT MUCH OF THIS NEWSLETTER WILL NOT BE APPLICABLE TO OUR OVERSEAS MEMBERS BUT THE GUIDELINES SHOULD HAVE FAR REACHING EFFECTS SO PLEASE HELP US FUNDRAISE.**

**Any articles for the next newsletter should may be sent by 1<sup>st</sup> September 2007.**

**Many thanks to Ivor, Tusti, Judith, Jan, our medical advisory team, GE, Innervate and especially all our members - together we can make changes.**

**With very best wishes to all our members for your continuing good health**

**THE HPTH UK TEAM**

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