



Support services since 1980

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Disclaimer:

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From the President's Desk



Welcome to our first newsletter for 2013. I trust you had enjoyable Christmas and New Year celebrations.

AASA will face an interesting and challenging year this year.

We have been discussing our messagebank service through which our valued volunteers respond to people seeking information and services concerning alopecia. Currently our phone number is not listed in the community section of the White Pages and we will be working on shifting from its current listing in the Business section under a better title. We are thinking of "Alopecia Helpline" and would welcome any comments you might have. Call the number or email us aasavic@gmail.com if you would like to give us some feedback.

I would like to recognise the contribution to the service made over a number of years by Sabine Bolick, who has moved on from her direct response role, but remains available to our team to discuss requests from parents of children with AA.
Thankyou Sabine.

Our work with the Skin and Cancer Foundation continues with Pat Crotty available to provide information and support at the Monday and Wednesday Hair Clinics. We are also able to hold our meetings at the Foundation in Carlton which is an excellent and welcoming central location for our members their family and friends. We thank the Foundation for this, in particular Jane English.

As President I would welcome talking with any of our members who would like to join our small volunteer phone response group and anyone who would like to join AASA with a view to becoming a volunteer.

All voluntary groups face many challenges in continuing their services and AASA is no exception, but with the support of our members and particularly our volunteers we look forward to working together towards a successful year helping all those facing the challenges of living with alopecia.

Best Wishes,
Garry Lonsdale
President.



Coping and the Psychosocial Impact of Alopecia Areata in Young Australians: An Exploratory Study Researcher: Louise Borg

AASA: Congratulations Louise on completing this interesting and important research project . If there's any info you would like to share about yourself as an introduction to your research?

Louise: I have a bachelor degree in Psychological studies and graduated with first class honours. I am a Registered Nurse and have been working in the field for 5 years. I also volunteer with disengaged youth within the local community.

- Can you tell us a little about how the study came about?

My supervisor A/Prof. Gerard A. Kennedy was contacted by Chel, the president of the AAAF, to conduct a study with regards to individuals with the condition AA and how we can better support this group of individuals. I was keen and interested in learning more about the condition and how we can provide optimal support to individuals with AA. I also felt it was important to recognise if there were psychological and social impacts from a diagnosis of AA.

- What were you hoping to achieve by conducting the study?

I was hoping to achieve information with regards to support and how to better accommodate individuals with AA and their needs. I was also aiming to identify how this particular group utilised coping strategies to facilitate with daily functioning. An important aspect of the study was to identify the psychological and social impacts of the condition, in this sample.

- Can you give us a brief summary of the study's outcomes?

Main outcomes:

While a minority of the sample presented with mild to severe levels, the majority of the individuals with AA coped well with the condition and did not demonstrate pathological levels of anxiety, depression or stress. The research explored themes regarding concerns about the condition AA. Emotional aspects (such as anxiety or stress), social interaction and appearance are examples of concerns discussed.

In terms of coping, positive styles were highly utilised in the group. Acceptance (89%), the use of emotional support (71%), active coping (67%) and positive reframing (67%) were equally, the third highest utilised coping style.

- How would you like to see the study results used?

I hope that the results are used to help those diagnosed with the condition. I especially would like to see that this thesis contributes information and knowledge to those newly diagnosed who may require extra support to cope with the condition. I anticipate that organisations can use the results to continue to raise awareness about the condition.

- Is there any other research which could follow on from your study?

A qualitative based research study to gather more information about living with AA and the impact it can have on not only the individual but their family too, would be of interest and quite beneficial. A gender analysis and breakdown with a comparison of the impact of the condition may be further research which could follow..

- Do you think there is any prospect of more research on AA at Victoria University?

Yes. I think a qualitative based research study may follow. This would require interviews and would provide a personalised view or opinion about the condition. There is also room for more quantitative research (statistics) because this is an important contribution towards research.

Our next members' meeting is

2 pm
23rd February

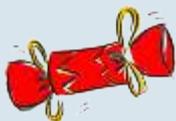
Skin&Cancer
Foundation
First Floor
80 Drummond St
Carlton
cnr Queenserry St

We hope to meet up
with you there!

Seeking information
or
support?

Phone
Alopecia Helpline
(03) 9513-8580.

One of our phone
volunteers will return
your call within 24
hours



Q. Why did the
doughnut seller retire?

A. He was fed up with
the hole business

- Are there any other comments you would like to make about the study?

It was a wonderful learning experience and opportunity that provided me with knowledge about the condition.

AASA: Thankyou Louise.

Back to School Resources

There are some great resources available for parents who may currently be dealing with 'back to school' challenges.

1. *"Back to School: Child Development and Alopecia Areata for parents of children with alopecia areata."* Dr Richard Long's webinar for the National Alopecia Areata Foundation in the US, is frank, informative and encouraging. You can download it (30+Mb) or listen online. It goes for an hour and includes a question and answer segment. (<http://www.naaf.org/videos/August22BacktoSchool.wmv>) If you are not on the net, call the Alopecia Helpline and we can provide you with a copy. (03 9513 8580)

2. Both the National Alopecia Areata Foundation in the US and the Australia Alopecia Areata Foundation produce a resource for parents
http://www.naaf.org/site/PageServer?pagename=support_resources_parent

http://www.aaf.org.au/uploads/SCHOOL%20PACK%20%20CONSOLIDATE%20VERSION%20Australia_2012.pdf

Bullying and Skin Disorders

'Appearance-related bullying and skin disorders' an article by Dr Parker Magin, was recently published in the medical journal 'Clinics in Dermatology'.

Dr Magin from the University of Newcastle in NSW, has written widely on the challenges faced by people with skin conditions. He notes that generally speaking, a lot of bullying is 'appearance-related'. Although skin conditions are often very visible and there are many misconceptions in the community about contagion, it's surprising there is not more evidence available about it. Dr Magin mentions a range of conditions which have been linked to instances of bullying, but there seems to be no data available in reference to alopecia. (There are many of us who would be able to offer our own experiences to remedy that situation! Ed.)

People who have experienced bullying and teasing in relation to their skin problem report it causes embarrassment, self consciousness, and it effects self-esteem, self-image and social exclusion. There is evidence that this problem can be associated with depression and anxiety, loneliness and impacts on quality of life.

Dr Magin concludes that, "Bullying and teasing are recognized as major problems in children and adolescents. Despite limited evidence, it is reasonable to conclude that children and adolescents with skin diseases are especially prone to bullying and teasing on the basis of their condition. Dermatologists and other clinicians should be aware of this and of the potential for bullying and teasing to effect their patients' psychological well-being.

Magin P, 2013, 'Appearance-related bullying and skin disorders', Clinics in Dermatology 31, 66-71.



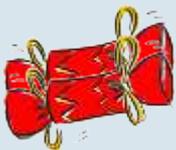
Q. What do you call a man with a seagull on his head?

A. Cliff

Seeking information or support?

Phone
Alopecia Helpline
(03) 9513-8580.

One of our phone
volunteers will return
your call within 24
hours



Q. What did the dog
get from eating all the
Christmas decorations

A. Tinseltitis

Clinical Photography: Ethics and Your Rights

The Medical Journal of Australia has recently tackled the complex issues around the question of who has control of, and access to, any photographs taken of you as part of your medical care. This is a medical, legal and ethical challenge.

Two of the four authors are associated with the Skin and Cancer Foundation (Associate Professors Peter Foley and Chris Baker) and the article sets out the appropriate ethical and legal standards which should be observed. The authors note that photography plays an important part in 'visually oriented' specialties such as dermatology and they are now an integral component in the practice of medicine.

Photographs are also used frequently in educating doctors and other clinicians and in research. More recently new technologies mean that images may be transmitted electronically as well as being stored as photographs in medical records. It is important the authors say "...that doctors should be aware of what is required when obtaining clinical photographs as well as the permissible uses of the photographs, particularly with respect to teaching and educational use, as well as research".

If the doctor can't take high quality photographs themselves, they should use a professional clinical photography service.

Legally, any information about you included in your medical record should only be collected when it is necessary for the reason it is being collected. This also includes photographs which, for example, might be taken to monitor the size of mole or the degree of hair regrowth. So it would not be a permissible for a doctor to photograph someone's really interesting tattoo unless it was necessary to have a record of some aspect of the patient's treatment and only after seeking the patient's permission and telling them who else may be seeing the photograph, and why.

So what can be expected by a patient before photographs are taken? First of all, your consent should be formally sought and the authors say that ideally, there should be a written consent form which sets out the uses to which your photo will be put and who will be able to see it. It should be made clear to you that you can withdraw consent at any time and how you can do this .

The authors note, "For consent to be lawful, it must be more than a perfunctory signature at the bottom of a preprepared proforma."...."The use of clinical photographs should then be limited to the purposes outlined in the patient consent, whether it be for clinical, educational or research purposes".

Whilst the article notes that this may be difficult to implement in a busy clinic and that taking photos is usually in the patient's best interest, the law, technology, medical practice, and patient rights are all evolving and this challenges both patients and clinicians to be aware of their rights and responsibilities.

Mahar, P.D., P.A.Foley, A Sheed-Finck and C. Baker 2013 Legal considerations of consent and privacy in the context of clinical photography in Australian medical practice Medical Journal of Australia 198(1)48-49.

Why don't ducks tell jokes when they're flying? Because they would quack up

What do you get if you cross a stereo with a refrigerator? Cool music

What must you know to be an auctioneer? Lots

How do snails keep their shells shiny? The use snail varnish

What do you get if you cross a skeleton and a detective? Sherlock Bones

The Michelle Law Story

Michelle Law is a young journalist, writer and blogger from Brisbane who wrote an essay on the ABC's "Drum Opinion" on December 3rd last year called "A bald woman's guide to survival" <http://www.abc.net.au/unleashed/4404420.html>. This was the basis of a performance by Michelle at a Brisbane TEDx event a couple of days earlier. TED events are presentations by people who have something interesting to say and who are seen as thought leaders. You can watch Michelle's presentation on YouTube (<http://www.youtube.com/watch?v=lrJom48KQA4>)

In the article and presentation, Michelle tells of her experience with alopecia areata which first appeared in infancy and then went away, only to reappear in her high school years. Because of her life-long experience with AA, Michelle explains she has developed a "...three-step guide to survival for bald women during times of crises" which is 'Know your worth', 'Embrace baldness', and 'Be visible'. Her presentation makes a strong statement about how she is determined that AA will not prevent her from leading the life she chooses.

Michelle wears a wig or other head covering sometimes, and sometimes chooses not to, the same as Johanna Rowsell (the UK Olympic gold medallist who featured in our November 2012 newsletter). The other options adopted by people with AA are to never wear head covering or to always wear some kind of head covering. These choices are equally legitimate and bravery and courage are part of all of them.

Michelle's story was given excellent coverage by local mainstream media, including The Sunday Mail in Brisbane and on Channel 10's The Project on Friday February 1st, and especially on Facebook on both local and international alopecia group sites. This coverage gives some insight into Michelle's personal commitment to raising awareness of AA in the community.

Michelle has a blog related to a writing project she is developing and you can add your story to her page.
<http://www.michelle-law.com/fully-sick/illnesses/alopecia/>



What's white, fluffy and swings through a cake shop? - A meringue-utang.

Where does a general keep his armies? - Up his sleeves.

What do you give someone who has everything? - Penicillin.

What is green, has a black cloak and holds up stage coaches? - Dick Gherkin

What is the difference between a buffalo and a bison? - You can't wash your hands in a buffalo

What is the nearest thing to Silver? - The Lone Ranger's bottom.

A New Article: Wigs and Quality of Life

The authors of an article from a medical school in Osaka, Japan discuss the important positive impact on the quality of life for the women in their study (Inui et al 2012). Forty nine women ranging in age from 14 to 76, who wore wigs or hairpieces responded to questionnaires.

Because there are no studies of the impact of wigs on women with AA the questionnaire they used was one which was developed for "assistive devices" more generally. An assistive device might be a hearing aid, or contact lenses. The women were asked about their satisfaction with their appearance when wearing a wig (the "assistive device" in this case). The researchers state that the results of the women's answers indicated that "...cosmetic satisfaction with wigs or hairpieces is important for assisting patients".

Finally they quote the recent British guidelines for the management of AA which recommend it is good practice for doctors to help patients address hair prosthesis and appearance issues, despite the fact there was, when the guidelines were written, no research evidence to show the outcomes of this help. (see Donovan et al below on the kind of information which will help doctors do this. It can be downloaded free from the internet).

The researcher notes that their study now has shown that, in their patients, wigs improved "perceived confidence", "adaptability" and "self-esteem" and therefore quality of life, and this was linked with the extent to which the women were satisfied with their appearance when wearing a wig.

Shigeki INUI, Takenobu INOUE, Satoshi ITAMI 2012 Psychosocial impact of wigs or hairpieces on perceived quality of life level in female patients with alopecia areata *The Journal of Dermatology* 40, 1-2

Jeff C H Donovan, Ron L Shapiro, Paul Shapiro, Matt Zupan, Margareth Pierre-Louis MD, Maria K Hordinsky, 2012, A review of scalp camouflaging agents and prostheses for individuals with hair loss, *Dermatology Online Journal* 18 (8): 1

Both of the sources below are excellent guides about practical ways of dealing with appearance issues mainly for women but also for men.

1. <http://www alopeciaonline.org.uk/wigs.asp>

"Buying a wig for the first time can be daunting. It can also be a major financial investment, so to minimise the risk of getting something you're not happy with, here's a guide to choosing the wig that's just right for you! You'll find some general pointers and tips too, to take the mystery out of wig wearing" Alopecia UK

2. The National Alopecia Areata Foundation (USA) 2012 **The Alopecia Areata Cosmetic Guide: Tools for everyday beauty**
http://www.naaf.org/site/DocServer/NAAF_Cosmetic_Guide_FINAL_lowres.pdf?docID=4221_10.1111/1346-8138.12040

For more local information in Victoria call (03) 9513 8580.



Q. What do you get if you cross a pig with a centipede?

A. Bacon and legs

Editor's Note:

The previous article on wigs and their positive contribution to the quality of life for women with AA, raised an interesting question for me. I read the story by Chrissie Swan in the Sunday Age on February 10th about being "outed" by a Woman's Day paparazzo for smoking whilst pregnant. Here's a portion of The Sunday Age article by Chrissie detailing how she felt and what lengths she went to, to keep secret her identity as a smoker.

"...As soon as I heard the clicking of the camera, I knew I would be forced to divulge, in public, my humiliating secret. I realised the whole of Australia would want to hang me, but what was worse was that I had kept my addiction a secret from my partner, my parents, my sisters, my best friends and my colleagues and now I would have to tell them too. Not one of them smoked. I was nauseous within minutes.

It is not easy to keep a secret from those around you. I'd hide my stash in a glovebox, under the car seat or in the zippered pocket of my handbag. I'd get nervous if my one-year-old started rifling through my bag. I wouldn't let my partner use my car.

I didn't want my loved ones to be repulsed by me. I didn't want to shock them or make them think they didn't know me at all. I didn't want them to think I was an idiot. I just didn't want them to feel about me the way I was feeling about myself. That I was loathsome".

Chrissie Swan, The Sunday Age, February 10th 2013 p.17.

How familiar that sounded to me and I'm sure to many others with AA. Wigs can be a mixed blessing!

We eagerly read the stories of individuals willing to be public about their hairloss. These stories can reassure us that we are not alone and remind us that many AA experiences are shared. But whilst making the choice to go public may mean escaping to some extent the curse of secrecy (And its comforts - It did work for Chrissie for a while), it also means taking on the challenges of being in the public gaze and, as we know, not all public AA stories are encouraging or are about what we would want for ourselves. There have been some very public and tearful consequences for Chrissie Swan but it is clear she has been rethinking the meaning of her experience positively. Her Sunday Age article concludes,

"Quit Victoria told me that the day after I confessed, calls to the Quitline doubled. Twice as many people called and said: "I don't want to smoke but I don't know how to stop. Please help me." They say my revelation caused this. That's something anyone would be proud to tell their kids".

You can read the whole article by Chrissie here -
Chrissie Swan 'Disgusting. Shameful. Illogical. A pregnant smoker butts out her demons', The Sunday Age February 10th, 2013 p.17
and online here

<http://www.theage.com.au/lifestyle/smoke-got-hold-of-my-senses-20130209-2e58h.html#ixzz2KRbEtTOK>

Pat Crotty (editor)

Pat Crotty prepares and edits this newsletter for AASA.

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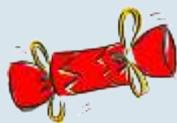
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We welcome comments and contributions from our readers.

Please include a contact email or street address with your letter or article.



Q. What do you get if you cross a snowman with a vampire?

A. Frostbite

All of which links us to the question.....

Are there other ways we can learn about "the alopecia experience"?

Some recent ideas and concepts about AA and hair loss

Recently a very small number of research projects have provided insights into the challenges and burdens of living with AA by asking a number of people with AA to talk about their experiences. This type of research is referred to by Louise Borg when she speaks of “qualitative research” the kind of research which requires interviews.

The advantages of this type of study include that, whereas when one person tells their story, we cannot be sure whether a few, or many people also have similar experiences but by gathering up many stories, common threads can be identified, for example, the different experiences, say for newly diagnosed people compared with those who have lived with alopecia for many years. Are they the same or different? In what ways? Are there different concerns for men compared with women? Or even are the quality of life impacts of different kinds of hair loss the same?

Discussing our experiences can be limited by the discomfort they cause us and our fears about causing discomfort to others. However, more opportunities to discuss our alopecia experiences could increase our understanding of our ‘selves’ and help us place hair loss in a wider social and cultural context. Qualitative studies may provide ways of talking about alopecia, something which is difficult when at the moment so little is known.

Here are 2 very brief summaries of interesting doctoral theses. It is noteworthy that both the authors have hair loss, Dr Dua has thinning hair and Dr West has Alopecia Universalis and both discuss how their personal experiences have led them to their research.

Dr Priya Dua’s 2011 thesis is called “Petals Falling Off A Rose”: The Effect of Hair Loss on Women’s Identity Performance. This is an interview study within the traditions of sociology. Very generally speaking, clinical research is concerned with what goes on inside the body, psychology largely with what goes on inside someone’s head, sociology and social psychology focus more on people’s ‘lived experience’ and the social and cultural context of that experience.

Dr Dua interviewed 26 women whose hair loss was one of 3 types, ‘thinning’ (9 women), temporary, ie. caused by chemotherapy or pregnancy (9 women) or AA (8 women). She focused on what impact hair loss made on the women’s identity, or ideas of their ‘self’ and what they did to project or “perform the identity” they desired. She calls this “identity work” and notes that “hair work” is a universal practice that people perform as part of their identity work. However it’s not a matter of just “doing anything” without any guidelines, this work is performed within social and cultural boundaries. These are the shared beliefs and ideas in a culture about what is feminine, womanly, beautiful, healthy and normal. We certainly have choices about what we do personally as individuals to create and project our identity, but this is generally performed within cultural boundaries. To be in some way outside the boundaries, to be too different, puts people at risk of being ‘discredited’.

This study is most interesting because it looks in depth at some differences between three types of hair loss and how the women interviewed responded to their type. In summary those with temporary hair loss, ‘waited out’ the period until their hair regrew by trying to look healthy and feminine. The women with thinning hair were ‘disconcerted’ by their loss, it affected their sense of self and was a change from their former self. They sought to look professional, acceptable and presentable whilst trying to hide their hair loss. By hiding their hair loss, the women with AA in the study, tried to meet the societal norms of femininity, beauty, normality and health by controlling their appearance to protect the image they portrayed to others. The author wonders whether seeking to have a ‘healthy’ identity is a better option than seeking the current culturally valued versions of femininity and beauty.



Q. What do you call someone who is afraid of Santa?

A. A Claustrophobic

Dr Emma West's 2010 thesis is titled "Bald Truths: Living and Coming to terms with Alopecia Areata Hair Loss". Although this too is an interview study and sociological, all the participants had AA and men were included in the group. Thirty three people were interviewed, 19 women and 14 men.

Dr West says of her own experience,

"It is difficult to convey and account for the depth of shame, humiliation and despair experienced at the sight of the patches as they continued to appear"....."Looking in the mirror I no longer saw myself, but a stranger with my face". Subsequently, because she was not revealing her hair loss she felt "shamefull and deviant" and "...like a fraud and was often beseiged by the nigglng fear of being discovered, or paranoia about having been already found out"

To convey the idea of change over time (and although the author is ambivalent about it), she uses the term 'alopecians' because it helps to describe her interviewees' change in identity over time. However this new identity which came through receiving a diagnosis, did not bring a sense of relief, partly due to the lack of interest in the condition by doctors.

She notes that, within AA groups such as support groups and online discussions, there are beliefs about good and bad ways of overcoming the problems caused through having AA. She calls this the presence of 'competing moral discourses', or debates, which are, "putting up a good fight" versus "reaching an acceptance". She suggests that for those trying to maintain their hopes for a full recovery, this tension is difficult.

Dr West's thesis is a nuanced and focused study of the experience of AA. One of the most interesting discussions is about the differences between men and women in the study. Her conclusion is that the men interviewed experienced the consequences of their hair loss equally as intensely as women, but differently. The focus for the men was body hair more so than head hair. The men also felt they had fewer options than women. Wigs and cosmetics were not used, and rather than conceal their hair loss to appear 'normal' they defended their self by creating a barrier, for example by wearing caps. This goes against the common beliefs about the gender differences in AA and hopefully will be further studied by researchers.

In discussing those people in the study with moderate to severe hair loss, Dr West identifies 4 courses of action they might take,

- Shaving off any remaining hair, which, though distressing, felt like regaining control of their body, at least temporarily,
- "Repairing" appearance by camouflaging hair loss by using cosmetics and wigs, and creating a barrier like wearing scarves, caps or hats,
- "Normalising" hair loss, by not being secretive but by integrating their alopecia into their lives and into interactions with other people whilst maintaining an appearance and identity they valued
- "Coping pragmatically", that is, by experimenting with ways of telling others about hair loss, experimenting with appearance management strategies and by applying the skills learnt. In this way they were able to act on their personal preferences and take into account particular situations in the ways they chose to cope. This helped them make sense of their life and to restore normality and control and find new meaning and identity. Dr West notes that some even embraced their new identity as an "alopecian" and enjoyed the feeling of being different.



Q. What is the best thing about deadly snakes?

A. They've got poisonality.

In terms of successful adaptation (feeling in control and being relatively comfortable with one's appearance), Dr West says, "Many participants acknowledged that in the longer term it was virtually impossible to reach acceptance whilst desperately seeking recovery". However, one respondent was angry and believed that some in his alopecia network had tried to push him into letting go of hope in getting his hair back and embracing acceptance, before he felt ready.

This thesis has much more to say about the alopecia journey and only a few ideas have been selected for discussion here. However Dr West flags a central issue for organisations such as ours to be sensitive to what people want in 'crafting' their unique and challenging path towards an increased sense of control and a redefined, positive sense of self.

**Would your day be different
if you felt a stronger, healthier person?**

Come to our next meeting

Saturday February 23rd
2 pm

Skin & Cancer Foundation in Carlton
First Floor
80 Drummond St
corner of
Drummond and Queensberry Streets

Join us for a social get together

and

let's talk about
a health promotion program
for people with alopecia

ALOPECIA AREATA SUPPORT ASSOCIATION (VIC) INC.

MEMBERSHIP REGISTRATION

Membership for Adult/Child with the Association for the financial year.....

Form of Alopecia of: Areata Totalis Universalis Other

Child Details Only (Please fill in)

Child sufferer's name..... M F

Parent of sufferer Supporter

Surname: Mr/Mrs/Ms/Miss.....

First Name:.....

Address:.....

..... Post Code:.....

Tel. No:..... Mobile:.....

Email:.....

Date of Birth (of sufferer):...../...../.....

Year Alopecia appeared:.....(approx)

Occupation:.....or/Pensioner No:.....

MEMBERSHIP CATEGORY:

Full Member: \$25.00 per year (July/June)
Associate Member: \$25.00 per year (Supporter)
Student/Pensioners/Children: \$15.00 per year (Minimum donation suggested)

Money order/cheque enclosed made payable to Alopecia Areata Support Association (VIC) Inc.
\$...... (No cash through the mail please)

Signature:.....Date:.....

Please mail to: AASA (VIC) Inc.
Marked Attention of:
Membership Registration, Treasurer
PO BOX 89
Camberwell VIC 3124

Office Use Only
Date Received:...../...../.....
Treasurer:
Receipt No:
Date: