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The Stammerer Trust

Charity Commission No. 265938

NEWSLETTER



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EDITORIAL

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EDITOR'S NOTE



Welcome to our Spring newsletter.

I apologise for the lateness of the newsletter arriving through your letterbox.

The pandemic has seen changes in the way we communicate: working from home, less face-to-face interaction (when we do we are wearing face masks) and social isolation which can affect our well-being. It seems talking is being replaced with typing. Job interviews, now increasingly held virtually, presentations, and speeches are daunting for many, particularly a person who stammers. 50 Million Voices (see page 9) are holding a 'Practice Interview' event to help stammerers in an interview situation. This summer, I am happy to announce, I am to be 'father of the bride' and faced with the prospect of making a speech. Whilst, no doubt, I will be anxious I will use techniques learned at The Apple House and plan to enjoy the day!

The last newsletter (Autumn 2020) was met with applaud especially the publication of the first ever issue. This inspired Richard Olney, a former attendee at The Apple House, to write an article titled 'How It All Began'. It is good to be reminded how the Stammer Trust has helped many people over the years. Next year the Stammer Trust marks its fiftieth anniversary. Now that's something to shout about!

If you have any comments, contributions or articles you would like to see published please send them to me by email to newsletter@stammertrust.co.uk before 9th September 2022.

Happy reading.

Andrew Barnes

Find us on Facebook: www.facebook.com/StammerTrust

FOREWORD FROM THE CHAIR



Thank you to those of you who attended our AGM held in November. The meeting was again held on the internet using MS Teams, a mode of communication we are all getting used to - some more reluctantly than others. The therapists are working hard and are now able to offer a combination of on line 1:1 therapy, on line group therapy and some face to face 1:1 sessions. Note that social distancing means that the NHS currently recommends that the Apple House should have no more than three people including the therapist in a session.

We all realise that if it wasn't for the highly transmittable Covid variant, Omicron, that services throughout the NHS would be progressing towards some sort of normality. However the new variant has resulted in significant staff sickness throughout the NHS, so we do need to be patient.

Looking forward the Stammer Trust have funding for equipment and therapist training, and as we learn to live with low levels of covid (so far undefined) we look forward to requests from the therapists for use of that funding, and the opportunity for our supporters to raise further funds.

We look forward to welcoming you hopefully in person at our summer meeting on 12th June and our AGM on 12th November.

Take care

Andy McCabe

Meeting dates in 2022 are :-

Committee Meetings

Saturday 12th March at 12 noon (virtual via MS Teams)

Sunday 12th June at 12 noon followed by Open Afternoon

Annual General Meeting

Saturday 12th November at 12 noon

Please see website for any last minute alternative arrangements

THERAPISTS REPORT

Adult Fluency Service report for the Stammer Trust

The last few months have afforded a unique perspective from which to reflect on my clinical practice. As I said in an earlier report, working remotely via MS Teams (which, for those who may not be familiar with this technology is similar platform to skype) has been a real boon for some clients, particularly those who in any case cannot easily access the Apple House.

As covid restrictions ease a little, though, it has reminded me of how good it feels to be able to see clients face to face once more, or perhaps I should say, mask to mask, since we still have this restriction on hospital sites and therefore at the Apple House. I think a large part of what eventually decides whether intervention is going to be successful or not hinges on the relationship between clinician and client, and there is nothing that comes close to helping that positive relationship than meeting in the calm and reassuring atmosphere of the Apple House.

The return to face to face has meant that I can once again run the popular 2-day intensive group follow up sessions. We ran one in January and I have a further one scheduled for later March. Five people took part in the January course with two of my speech language therapy students from Reading University assisting. It was unfortunate that due to social distancing restrictions we could not all fit in the Apple House and instead had to run the course from a rather characterless room within the Warneford hospital. Nevertheless, the feedback from the attendees was overwhelmingly positive and we all enjoyed escaping to meet offsite in Costa's Coffee House in Oxford town centre on the Sunday morning. To do some transfer exercises. I will ask one of the attendees to write a report for the next bulletin.

In my last report I mentioned that the waiting list was continuing to rise. This is a trend that shows no signs of levelling off. Clearly there is huge demand for the service, but it is concerning that people are having to wait on the waiting list for much longer than they should.

Finally, I need to report that a formal collaboration between myself (with my University of Reading hat on) and benetalk (a company designing an app for people who stammer and who initially won funds from the stammer trust to help start up their company) has come to an end for the moment. I remain, though, in close touch with this company and continuing to advise them on the development of clinical aspects of their app. This company, ST members may recall, was able to begin to build its product having won an initial grant award from the ST around four years ago. Benetalk's CEO, Jordi Fernandez and technical officers are people who themselves stammer, and have never forgotten the boost that winning the Terrence Barry grant gave them. They now continue to expand their app, the ultimate goal of which is to provide a therapist free option for those who stammer and cannot access clinician-led therapy. The app is still very much work in progress, but they now have a formidable technical team working with them and its development is moving along rapidly. At the moment, a key feature of what the app can do is monitor speech rate, something that is of considerable benefit to a number of people who stammer – particularly keeping an even pace when under moments of pressure. I am optimistic that this technology will be a valuable tool for people who stammer, worldwide. I am currently incorporating this app into my therapy for some clients; it is really gratifying to see the benefits that collaboration between clinicians and technology can bring.

With grateful thanks again for all your support over such a difficult time,

David Ward

Speech and Language Therapist

Spring 2022

HOW IT ALL BEGAN

Next year it will be fifty years since the Apple House opened as a centre for speech therapy at the Warneford Hospital, Oxford. May 2023 will mark the fiftieth anniversary of the foundation of the Stammer Trust. This is not the place to attempt a review of all it has achieved since the mid-1970s, but in reading the first issue of this Newsletter, dated May 1975 and reproduced in Issue no 117, I was reminded of the circumstances preceding and surrounding the events of 1972-3, and thought I would jot them down while I am still able to do so. Members less familiar with them may perhaps find them of some interest, and it is also an opportunity to pay tribute to some of those from whose work and commitment we benefit today.

The story begins back in 1964, when a course for adult stammerers was set up at the Warneford. The first therapist was Miss Ann Wallace, succeeded two years later by Mrs Gerda Wilson. It was a research project, originally based on earlier published work centred on the technique of syllable-timed speech (timing every spoken syllable to the tick of a metronome). The Warneford acted as its host thanks to the personal interest of Dr Seymour Spencer, one of its senior consultants. It was he who was clinically responsible for the project, and who interviewed patients referred by their GPs from all over the country before they were accepted for the course.

The emphasis was on group treatment, and on maintenance during the follow-up period that followed each initial two-week intensive residential course. This was demanding for a singleton, part-time therapist, as it was for the patients, but Gerda Wilson became totally committed to the project, even working through a two-year period when there was no funding for it. By the early 1970s she had treated, and inspired, a large cohort of patients, with whom she kept in touch and whom she welcomed back for refresher courses when needed. (My own initial course was in April 1967. I am still in touch with one of my fellow-members. Another participant was the late Terence Barry, whose name will be known to current members, and beneficiaries, of the Trust.)

This was the background to the course of April 1972, which had to be held out of doors, in the hospital's grounds, in the absence of any available treatment room. Luckily the weather was fine, but the group was horrified by this hand-to-mouth situation, and spotted a small stone out-building that might if converted serve as a place in which to hold the courses. (It had latterly been used as an apple store, but had originally been the hospital's morgue).

The group decided to form an Oxford Stammerers' Action Group (OSGAG), with the immediate aim of taking over the Apple House. Led by Michael (Mick) Peake, later a hospital doctor, and Arthur Marsh, a young architect, it secured the permission of the hospital authorities in July 1972, and by October the upper room was ready for use by the next course. During 1973 the ground floor was turned into a small kitchen and office, and a small extension was built to enlarge the entrance space and provide a cloakroom. The building was officially opened at a ceremony in April 1974.

The Group had not been able to afford a professional builder, and they did much of the work themselves, with funds raised by fellow-patients and supporters. I remember a patients' reunion at the hospital in October 1972, at which money was given or pledged, and a "Speak-In" at the Apple House in July 1973, at which speakers were sponsored to give talks on subjects of their own choosing at so many (new) pence per minute. (My subject, on which I spoke for

38 minutes, was Relapse.) Support from the hospital had been important. It matched OSCAG's fund pound for pound, and agreed to meet the running costs of the building.

OSCAG did not rest content with this achievement. It aimed to promote the treatment of stammering more generally, and to foster further treatment-based research. To this end it decided to set up a charitable trust. It was ably assisted in the preliminary work by Colin Bessant, a graduate of one of the 1966 courses and an Oxford-based accountant with useful local contacts; and in due course the scheme was approved by the Charity Commissioners. A trust deed was executed in May 1973, the original custodian trustees being Alderman Conners (Lord Mayor of Oxford 1972-3), Mr Norman Smith (sometime Secretary of the Isis Group of Hospitals), Dr Seymour Spencer, and Miss Catherine Renfrew (Chief Speech Therapist, United Oxford Hospitals). Seymour was of course the trustee most closely associated with the working of the trust, but Catherine Renfrew's support and wise counsel were also invaluable. It was always intended, however, that the day-to-day business of the trust would be conducted by a committee of management. In the earlier years Bryan Wilson, Gerda's husband, played a vital and much-appreciated part as its chairman.

Today the Stammer Trust continues to support speech therapy and research into stammering. Nobody reading the Newsletter can fail to be impressed with the value and importance of that work, as relevant today as it was in the 1970s. The Newsletter, too, plays an essential role in keeping its members in touch with the Trust and with the wider speech therapy world. How attractive and well-presented it is, and what a long way it has come from Issue no 1 (for which I must take editorial responsibility)! Congratulations to its current editor, and every good wish for the future.

Richard Olney

MINUTES OF THE ANNUAL GENERAL MEETING [EXTRACT]

The forty-fourth Annual General Meeting was held on 13th November 2021 virtually by MS Teams due to Covid-19.

Chair's Opening Remarks by Andy McCabe

The meeting was again held via the internet (Teams) due to Covid-19. The Speech & Language Therapy (SLT) service has continued operating via ZOOM and many clients have adapted to this way of working.

Funds were allocated to Rachel Kennell to help with training other generalist SLT to work independently and to offer an integrated service county wide. This funding has also enabled Rachel to benchmark the service against other counties.

The publication of the newsletter has been delayed as the editor is still awaiting articles, when received it will be printed and distributed. The delay means reports from this AGM can be included.

Minutes of the previous meeting

No corrections or additions

Regarding painting work on front door – no further deterioration but no scheduled work as yet. Gift aid - This is still to be completed by the Treasurer and Membership Secretary. Last Gift Aid claim was submitted 4 years ago and there is now a possible claim of £600 for the funds.

Election of Trust Members

No new members were proposed. Jordi is to stand down. We all noted his enthusiasm during his time on the committee. He has been grateful for the help and support by the Stammer Trust to Benetalk.

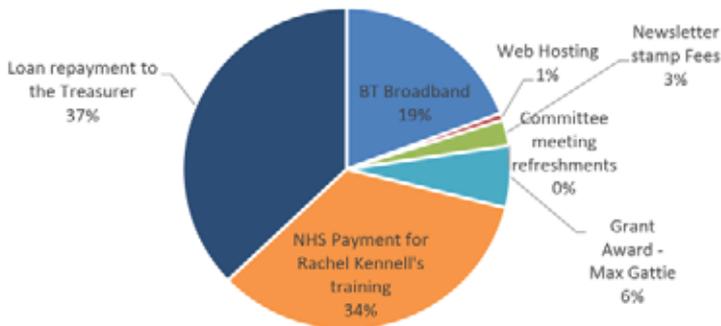
Committee returned unopposed.

Treasurers Report

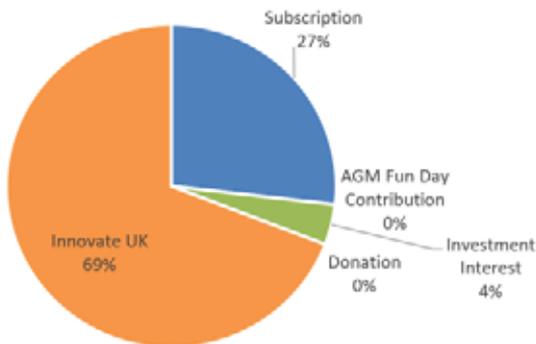
The Treasurer outlined the finances for the year ending 31st May 2021. Our annual return has since been submitted to Charity Commissioners.

The majority of income is from subscriptions and reimbursement from Innovate UK (project with BeneTalk)

2020 - 21 Expenses



2020_21 Income



Telephone costs relate to the internet provision and will be a lower cost next year as the BT contract has been changed. The SLT service no longer require a landline as they are supplied with mobile phones.

Investments – HSBC account still had out of date signatories. This has now been changed and the Chair will complete the update. Our Virgin Money account also needs to be updated to secure the best deal.

Terence Barry Grants Awards

The scheme has run six times - every other year. The donation Terence Barry bequeathed has now been used. Grants will be paused for further review and discussion.

Dates for the next meetings were discussed.

Everyone was thanked for attending the meeting and closed.

IN THE NEWS

Stammering may be linked with anxiety in some children and adolescents

Children and adolescents who stammer report elevated symptoms of anxiety compared with non-stammering peers, according to a new review of evidence led by UCL researchers.



The study, published in the *Journal of Speech, Language and Hearing Research* and also involving the Western Norway University of Applied Sciences, combined and re-analysed findings from 11 previous studies that had compared children and adolescents (two to 18 years) who do and do not stammer on symptoms of anxiety and depression.

Although there was substantial variation in reported anxiety symptoms across studies, overall, children and adolescents who stammer report higher anxiety symptoms than peers. There were too few studies concerning depression to reliably comment on risk for youth who stammer.

Stammering affects around 5 – 8% of school-aged children. Heightened risk for anxiety in adults who stammer is well documented, but little is known about the onset of anxiety in this population.

Lead author, PhD candidate Ria Bernard (UCL Psychology & Language Sciences), said: “An important finding from this review is that children and adolescents who stammer are not a homogeneous group. It is likely that a multitude of factors are involved in both risk and resilience for anxiety in this population. We were unable to robustly look at potential moderating factors with the data available and so there is a need for further research in this area.”

The high variability in outcome means that not all young people who stammer experience anxiety. The authors suggest that elevated anxiety may reflect other risk factors such as

exposure to bullying, access to therapy, or family history of anxiety and depression, which may increase risk or resilience in children and adolescents who stammer. Few studies reported these additional variables, so it is currently unclear what factors contribute to this increased risk.

Most importantly, these findings cannot address the impact of intervention on anxiety. Intervention approaches may focus on improving fluency, strategies for coping with dysfluent speech, or a combination of the two. The study results do, however, highlight the need to carefully monitor the mental health and well-being of children and adolescents who stammer.

Action for Stammering Children Charity who funded this research in collaboration with the Economic and Social Research Council (ESRC), said: "The findings from this review are important when thinking about how we best support children who stammer and their families. Early identification and access to Speech and Language Therapy services are vital to improving well-being and ensuring that children receive the support that they need."

The authors emphasise that the studies reviewed predominantly examined anxiety in mid-childhood. Additionally, the lack of longitudinal studies make it hard to understand why some children who stammer experience greater symptoms of anxiety while others do not. Ideally, longitudinal studies that follow large groups of children who stammer over time would help us understand the association between stammering and anxiety over the course of development.

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<https://actionforstammeringchildren.org>



Author: Ria Bernard (UCL Psychology & Language Sciences) Jan 2022

Link to article: <https://www.ucl.ac.uk/news/2022/jan/stammering-may-be-linked-anxiety-some-children-and-adolescents>



50 Million Voices (www.50millionvoices.org) is an ambitious global community transforming the world of work for people who stutter. With leaders in 15 countries and 6 continents, we work with people who stutter, employers and allies.

Our work helps people who stutter enjoy a fulfilling working life and enables organisations to benefit from unleashing the talents of the 50 million people of employable age globally who stutter.

We share best practices, run events involving people who stutter and allies who don't stutter, and help employers create stuttering-friendly working cultures.

Interviews are particularly stressful for people who stutter due to the difficulty in communicating fluently in time-pressured situations where so much can hang on the outcome. This is compounded by most interviewers having little experience of candidates who stutter, or of getting the best from them.

To date, we have run four Practice Interview events for people who stutter and allies who don't stutter. Three have been in English and one in French. Our interviewers have come from public, private and third sector employers. Our next 'Practice interview event for people who stutter' is from 9 – 12 May 2022. Applications open on 11th March and closing on 11th April.

Twitter: @50MillionVoices and **LinkedIn:** www.linkedin.com/company/50millionvoices

THROUGH THE ARCHIVES

Continuing the theme Issue 2 from 1975 outlines four intensive and refresher courses held during the year and the ambitious plan to extend the Apple House to have larger therapy rooms and an eight-bed dormitory.

NEWSLETTER

No. 2 - December 1975

BETTER LATE THAN NEVER

The Editor is writing these lines sitting at the kitchen table in the Apple House, as a relaxation after a hard day's chat. Before him, sharing the table with his notes and drafts, are objects familiar to many - a tray of yellow earthenware mugs and saucers, a ticker-box of a now outmoded type, and a key to which is attached, by a bootlace, one of those beautifully simulated apples which look as though they might be made of real marzipan. There is also a Bible in very small print, indicative of rehearsals for the carol service.

We are not, therefore, so very far from Christmas, and the first Newsletter came out as long ago as May. Why the long pause? Had the Editor forgotten what he wanted to say next, or had we all gone to sleep during that tediously hot summer? The truth is that the next meeting of the Trust, which was to have taken place at the end of May, was postponed until the autumn. A Newsletter is pointless unless it has news, so the Editor waited, hoping that in the meantime the subscriptions and contributions would flow in.

Terence Barry reports a trickle of subscriptions - not as many as we had hoped, but enough to make it worthwhile to carry on. Those who intended to send their forty-five pence but did not remember to do so are still not too late. A cheque or postal order for that sum will entitle you to receive this and the next two issues, and you should send it to Terence

There has been an almost complete drought as far as contributions are concerned. The Editor (who does not want to fill page after page with his own insipid waffle) is still as eager as before to receive anything from a one-sentence piece of news to a five-hundred word article. Please write to him (Richard Olney)

NEWS FROM THE TRUST

There were two main subjects for discussion at the meeting of the Management Committee on Saturday, 22nd November. One was the publicity leaflet, which has been evolving in the expert hands of a sub-committee, consisting of Colin Bessant, David Montgomery and Peter Moreve. Proofs had been received from the printer, but it was reported that some last-minute adjustments to the text had been found necessary. These alterations will not, however, delay the leaflet long, and it should be ready to go out in February.

The appeal will be a selective one, and readers of this Newsletter need not feel apprehensive lest the leaflet should come thudding through their letter-boxes in a few weeks' time. As mentioned in our last number, the initial targets will be a group of institutions (industrial companies, grant-making bodies, and so on) that have funds to deploy in this particular field. The leaflet contains a concise description of the progress of the treatment, the formation and aims of the Trust, and the design for the new building. A photograph of the group in session is featured, and so is Patrick Hannay's now well-known poem 'Eyes'.

NEWS ABOUT THE TREATMENT

We said in our last Newsletter that Gerda would be able to take three initial courses during 1975. In fact there were four courses, making the year a record one in the number of patients treated. The total has now reached 187 since the start of the Oxford treatment. Yet more and more stammerers are getting to hear about the courses, some through their own doctors or speech therapists, others through broadcasts or newspaper articles. The waiting list now stretches into 1978, and one of the members of the most recent course had to wait over two years from his referral to the start of his treatment.

The course in April consisted of six men and one woman. Three came from in or near Oxford, one from Sheffield, one from South Wales and two from Somerset. The September course had, again, three patients from the Oxford area, the others coming from London, Gillingham (Kent), Cheltenham, Wolverhampton and Wallasey. The December group was unusually small - six men - and mainly drawn from the Midlands.

Each initial course has its own follow-up and refresher meetings, so that 1975 has been even more busy for Gerda than at first appears. The April group was refreshed in July, and the September course will re-assemble to report on their first six months progress next March. In September (almost immediately preceding an initial fortnight!) a two-day intensive refresher course was run - 9 a.m. to 9 p.m. on both days.

Gerda would like to hear from people who feel in need of refreshment, and would like them to state whether they would prefer an intensive two-day course of the September type or a (slightly) less intensive week.

The two latest courses serve to emphasise the need to build our own living-in accommodation as soon as possible. The September group had to fend for themselves. The December patients were given beds on Cooke Ward - for which of course they were duly grateful. But intensive speech therapy is tiring enough without bumps in the night, suffocating heat, and the snoring of one or two oblivious fellow-patients.

Perhaps because the December group was a small one, it seemed to have an unusually high tolerance for visitors. In fact it thrived on them. Among those therapists and friends who gave much appreciated help, were Sue Mills, Elizabeth Anello, Betty Wilson and Patrick Hannay. The ever-strengthening links with the Churchill Hospital speech therapy department are a most encouraging sign for the future expansion of the Warneford treatment.

-oOo-

The new ticker-box is now available. It was launched by a B.B.C. programme on 16th October in which Gerda and Michael Barratt, of Nordis Industries, took part. Bryan Wilson has written an explanatory article, which has appeared in the speech therapists' Bulletin, and which will be reproduced in the next number of this Newsletter.

COURT AND SOCIAL

A carol service will be held (for those who have attended courses during 1975) on 20th December at the Warneford Hospital chapel.

-oOo-

Neil Barker was one of the first patients to put his new-found fluency to work in what might be called, in S-T jargon, the courtship situation. He and Eileen were duly married, and they now claim to have had the first 'syllabic' baby, John William, born on 9th November.

THE PROPOSED NEW BUILDING
- OUR ARCHITECT'S DESCRIPTION -

The new building will be essentially a large extension of the Apple House, but it will inevitably have a character of its own; a character which will reflect both the intimate atmosphere of the existing building as well as the needs of a larger centre.

The building will attempt to encourage group therapy by the way the accommodation is arranged and to express this in visual form. It will have to house a variety of activities in a fairly small space - 280 square metres or 3,000 square feet - while still retaining a domestic feeling.

The conflict between a patient's desire for privacy and the stimulus to be gained from living "in community" for an intensive period of up to two weeks has to be resolved, as has that between the inward-looking nature of the typical treatment course and the need to encourage visits from observers such as therapists and students. Moreover, the building has to be a worthy addition to a generally attractive group of hospital buildings.

The accommodation will be arranged on one level attached to the south face of the Apple House and the adjacent high stone garden wall. It will consequently overlook the cricket field and the tree belt beyond. A number of footpaths at present converge at the eastern corner of the Apple House, and the entrance to the new building will be placed here. The glazed entrance hall will have a small office for a secretary/receptionist on one side, and on the other a new door into the Apple House through what is at present an office. The ground floor of the Apple House will be re-arranged to give more movement and cloakroom space, the kitchen "shrinking" to become a tea bar or "galley". The existing spiral staircase will still lead up to the treatment room, which will now have a secondary function, but become a secluded quiet room as well.

Directly in front of the entrance doors to the main building a short passage leads to the new treatment room. This room is in turn screened from a dining area, and has a glazed side leading into a small walled garden. The treatment room can thus be intimate in character, when screened off, with its fireplace in the corner; it can be part of a larger space accommodating audiences or gatherings; or it may be opened to the air in summer. Storage space is provided for chairs, tables and bulky audio-visual equipment. The treatment/dining area covers 63 square metres or about 680 square feet, and will seat 40 for a meal.

The kitchen is planned for use either as a snack bar or to provide a comprehensive menu. The southern corner of the building next to the kitchen will contain a bedsit/office for the senior therapist with views over the cricket field as well as access to the private garden.

The dining area and main entrance are further linked by a secondary space which gives access to a polygonal dormitory for eight men patients. It is here in the dormitory that the group aspect of the course is most obviously symbolised and, hopefully, fostered; but it is felt that an appropriate arrangement of furniture will give an acceptable degree of privacy. Nearby is a double bedroom for women patients or for visitors, and a "unisex" ablution and bathroom unit, again in keeping with a relaxed family feeling.

The dormitory is the focal point of the scheme: it is seen from nearly all directions, and "turns the corner" from the Apple House to the elevation facing the field. It is articulated from these by glass links, which will contrast with the local stone it is hoped to use. Initially at least the roofs of the various parts of the building will step down in stages from the Apple House to the garden wall, although when the expected second phase is built above the first, the polygon of the dormitory will be increased in height to make a true dominant focal point of the composition.