**Meeting of the SWAG Network Brain and Central Nervous System (CNS) Clinical Advisory Group (CAG)**

**Wednesday, 12th October 2022, 13:00-16:00**

**Engineers House, The Promenade, Clifton Down, Bristol BS8 3NB / Hybrid MS Teams**

**Chair: Mr Venkat Iyer (VI)**

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| **REPORT****(To be agreed at the next CAG Meeting)****1. Introductions and Tessa Jowell Foundation update**Please see the list of attendees and apologies uploaded on to the SWAG website [here](http://www.swscn.org.uk/networks/cancer/site-specific-groups/aswg-site-specific-groups-2/brain-central-nervous-system-ssg/). Since the last meeting, held last in November 2020 due to workload pressures caused by the COVID-19 pandemic, Bristol Neuro-Oncology Group (BNOG) has been recognised as a Centre for Excellence for Brain Tumours by the Tessa Jowell Foundation. The service was noted to be unique in having a Brain and CNS Clinical Nurse Specialist at a District General Hospital (S Levy at YDH), providing care for patients locally while working closely with the BNOG central team.  **2. Management and Pathways for CNS Lymphoma**Referrals for CNS Lymphoma are made to BNOG MDT from multiple routes and most commonly straight from emergency departments or local general medical teams.BNOG offers a diagnostic service only for these patients; there are often uncertainties and delays in the patient pathway while the team try to establish if a biopsy is necessary/appropriate.Consultant Neurosurgeon V Iyer wants to liaise with Haematology Treatment Centres to improve management of CNS Lymphoma pathways and has invited Consultant Haematologists to the meeting today to commence this process. Although communications with the haematology teams are prompt and work well once a diagnosis is made, Consultant Haematologist L Percy feels it would be helpful to clarify the appropriate cases to send for a biopsy as decision making in this area can often be very complex. The main challenge is for the patient group where radiological assessment is indicative of high-grade lymphoma but, due to performance status (PS), it is unclear if the patient is fit for a biopsy and if this would be in the patient’s best interest. Referrals to BNOG can be received from all hospitals within the SWAG region (GRH, NBT, RUH, SFT, UHBW, and YDH) and some patients are referred from further afield, and so often the team will not have seen the patient to assess their PS.Consultant Neurosurgeon N Barua has had cases of high-risk patients that haematology services are not able to accept responsibility for until a tissue diagnosis has been confirmed. It is possible for the surgical team to counsel against the risks of biopsies and surgical intervention, but not to rationalise this against the CNS lymphoma treatment options. Biopsies can have a detrimental effect on neurological and performance status and ideally the implications of treatments recommended by the haematology team would be helpful to know about prior to diagnosis.It is agreed that access to advice from haematology about treatment risks pre-treatment should be made readily available and this will be discussed with the working group.It was clarified that haematology are not able to commence treatments without a tissue diagnosis as radiology is not always accurate; there have been cases where, despite the radiology looking compelling for CNS lymphoma, they have turned out to have a different diagnosis.Neuropathology would prefer that steroids are not administered before the patient is referred for biopsy as this can make the lesion shrink and affect biopsy rates. This commonly makes the outcome of the report ‘suspicious for lymphoma but non- diagnostic’. This is particularly concerning if the biopsy leaves patients in a deteriorated neurological state. Communication with Haematology either at or before the BNOG MDT would be ideal, particularly for the patients who are referred as an emergency. Consultant Oncologist L Hawley bridges this gap across the Bristol MDTs and ensures that urgent cases discussed at the Wednesday BNOG MDT are referred to the Thursday Bristol Haematology MDT. Contact details of regional lymphoma and neurosurgery experts will be compiled to set up the working group in the next few months. Answers to frequently asked questions will be put together by the working group.**Action: The working group will be established to pull together guidelines that will improve communication pathways in the new year.**Both the Brain & CNS and Haematology Clinical Advisory Group representatives were grateful that this line of communication had been initiated.**3. Service Developments****3.1 PhD Project Updates****Presented by N Barua**Two PhD projects are underway in collaboration with the University of the West of England, part-funded by the SWAG Cancer Alliance, both of which have Quality of Life (QoL) outcomes. The first student started in April 2022 aiming to further develop the test used in brain tumour awake surgeries in speech areas of the brain to make it more relevant, sensitive and specific. A literature review is currently underway which is progressing well. The methods currently used during awake craniotomy have some drawbacks as the verb generation test may not be relatable to many of the general population and needs to be updated. This may in part be informed by a Dutch test if a translation can be ratified.The second project is to develop non-pharmaceutical interventions for management of fatigue in brain tumour patients. The negative impact on QoL in this area is known to be very significant and there is currently nothing that helps. Multiple experts are involved in the project, including physiotherapists, occupational therapists, an expert in chronic disease management and the Brain Tumour Support Charity. Initially, a literature review will be undertaken followed by structured interviews with patient groups, aiming to develop a protocol for a pilot randomised trial of non-pharmacological personalised interventions that will provide physical, emotional and psychological support. Assistance from the team to help recruit to the trial would be much appreciated.All brain tumour types will be included; it is expected that the needs for low and high tumour grades will be very different.From a user representative perspective, A Holness fully supports the project given his family member’s experience with fatigue, especially at the point in the pathway when oncological treatments meant that they were sleeping most of the time; anything that could help during the whole treatment pathway would have been appreciated.Both projects will run over three years. Initial findings will be presented by the PhD students at a future meeting.**Action: Potential agenda item of PhD student update of Research Project progress****4. Research****4.1 NIHR Clinical Research Network Update****Please see the presentation uploaded on to the SWAG website****Presented by C Matthews**Research Delivery Manager for the West of England Clinical Research Network,C Matthews provided national research activity which showed that 3,796 participants recruited to Brain and CNS trials from April 2021 to March 2022 and 1,762 recruited in the financial year to date, with an even split between observational and interventional trials. Over the last financial year, national and regional trial recruitment was very successful. Regional recruitment has mirrored national trends, with a dip during the COVID-19 pandemic. Fourteen trials are open within the SWAG region as detailed in the presentation. The NIHR has set up an Associate Principal Investigator (PI) 6 month in-work training scheme to encourage health professionals from the multi-disciplinary team who are not currently involved in research to gain experience alongside experienced PIs. The Tessa Jowell BRAIN MATRIX platform study is in the scheme. CAG members are encouraged to complete the application form which is available on the website:<https://www.nihr.ac.uk/health-and-care-professionals/career-development/associate-principal-investigator-scheme.htm>It involves completion of several online modules. Feedback so far has been positive.Results from the Participant in Research Experience Survey (PRES) for 2021/2, which had nearly 2,000 responses from 97 studies across 22 specialties, including cancer, were rated well; 93% indicated they would take part in research again. 93% also felt they had received all the information they needed. 92% felt researchers had valued their contribution. Comments included: research participation was easy and well organised, research staff were friendly and professional, and participants felt they were contributing to improve healthcare for others.Recommendations include improving access to test results and contact details of the research team and access to parking and appointments out of working hours. The CRN will be looking at ways to address these issues.Useful links and contact details for the Research Delivery Team are within the presentation. **4.2 Identifying and validating molecular targets in nervous system tissue** **Presented by K Kurian**Consultant Neuropathologist K Kurian is the Chief Investigator for a study that will address the fact that, at present, not all patients are consented for the brain tissue not used for diagnostic purposes to be used in other areas of research. Resolving this complex problem would help make the best use of the emerging technologies, which it is hoped will further tailor treatments according to individual tumour biology.The study ties into the aspirations of BRAIN MATRIX and the strategy in Cambridge to undertake rapid Whole Genome Sequencing (WGS) which is funded for all Brain Tumours and provides patients with new targeted inhibitors. It will provide a backbone to ensure that all patients are asked for permission to store tissue for research and have equity of access to WGS and any relevant available trials. To facilitate this, consent processes will be streamlined. It will also seek to improve timely access to the test results and how these can be interpreted.Liquid biopsies (blood samples) will also be taken to look for proteins and other biomarkers that may be useful, for example, glial fibrillary acidic protein (GFAP) may be present in blood before a Glioblastoma Multiform is present on a scan.A further aim is the development of intraoperative diagnostic biomarkers so that it is possible to inform the surgeon of the type of tumour during the operation. Historically, there were issues with tissue and blood bank storage which have since been resolved. Frozen tissue is required for WGS rather than paraffin embedded.Consent needs to include a record of discussion to clarify that germline alterations could be identified which may have consequences for the patient’s family members. User Representative A Holness reported that, due to the rapid pathway that his family member experienced, surgery and chemotherapy had been given before clinical trials were considered. K Kurian had since offered the opportunity for A Holness to consent for the remaining brain tumour tissue to be used in research activity to help others, which would have been in line with his relative’s aspirations. The difficulties with considering consenting to trials at the point of diagnosis, when there is so much information to process, was recognised although the ideal time would be when the patient is consented for surgery.It is easier for the paediatric oncology team to achieve this due to the increased number and length of patient/relative contacts.A slimmed down consent process integrated into the surgical consent may help, although a higher level of consent is mandated rather than a simple opt in option. Getting consent to store the tissue upfront as part of the surgical consent, with the caveat that a more in-depth consent process will be undertaken to explain this further with input from a dedicated research nurse, may be the most realistic approach given the difficulties of information overload at diagnosis.**Action: V Iyer and K Kurian will discuss how to progress this further****5. Patient Experience****5.1 National Patient Experience Survey Results (NCPES 2021)****Please see the presentation uploaded on to the SWAG website****Presented by L Wilks**Results for the SWAG region from NCPES 2021 were published in July 2022. The mandatory survey, which is commissioned and managed by NHS England, is used by NHS E to monitor progress in delivering cancer care, improved patient experience and quality improvements. The majority of results within the presentation reflect the patient experience for adults across all cancer sites as it is not possible to get an accurate picture / make any generalisations specifically relating to Brain and CNS patients due to the low number of responses.**Action: To see how many Brain and CNS patients were sent the survey due to the low number of responses**The survey doesn’t capture those patients who have just had outpatient care, but they will be sent the survey if they had a surgical inpatient procedure in NBT between April-June. The survey provider Picker has been contacted as there are some discrepancies in the data. Picker is hoping to include outpatients in future iterations of the survey.The survey has also not received sufficient responses to reflect the regions ethnic diversity and further work needs to be undertaken to address this. The majority of results were very positively rated, being greater than 90% and higher than the national average.Two scores fell below 60% for the questions on long term side effects being explained in a way that they could understand (50%) and if the patient had a review of cancer care by their GP practice (20%). Lead Cancer Nurses have pulled together the priorities that each Trust will work towards in response to the overall results.NBT have a local survey of the surgical patient experience; it would be ideal to do the same for chemotherapy and radiotherapy with the same questions so results can be compared. There is a CNS forum that meet regularly where results could be fed back.User Representative feedback is that the positive and negatives from the NCPES results ring true - in particular the lack of follow up from a Primary Care perspective. **Action: L Wilks to set up a working group to develop a regional patient experience survey, ideally digitised, with involvement from the Brain CAG Patient/User Representatives.** **5.2 Neuro-Oncology Prehabilitation Service****Please see the presentation uploaded on to the SWAG website** **Presented by C Moran / E Guiney**Neuro-Oncology Specialists, Physiotherapist C Moran and Speech and Language Therapist E Guiney, have commenced a two-year prehabilitation pilot. The first few weeks have entailed planning the patient referral pathways; the full launch will be on 31st October 2022. The aims of the service, service resource, delivery and outcomes are detailed in the presentation.It is planned to have discussions about the patient’s home set-up and look at what equipment and care will need to be provided pre-surgery, which will hopefully help to reduce length of hospital stay.Baseline assessments can be provided to inpatient teams so that they understand the patient’s pre-operative abilities. Support will be provided for patients to help optimise their pre-operative condition and prepare them for post-operative consequences. As the team is not full time, they intend to be sufficiently flexible in order to meet the needs of the service wherever possible. While it is hoped that the prehab clinics will run alongside the Consultant clinics, this will be assessed to see if this is the appropriate time or if this should occur at a different time. Feedback from other prehabilitation services suggests that, although it is a lot of information on the day of diagnosis, having an initial prehab discussion is beneficial for patients as it gives them something practical to focus on.The service will be adapted as necessary in response to feedback.Patients will be reassessed post-operatively wherever possible.The team are working with UHBW on a prehabilitation dashboard where all prehabilitation activity can be shared. They have also formed links with South Tees and Leeds to get advice from their well-established award-winning services and have also established links with community services, such as the Neuro-Oncology service in Gloucestershire who are happy to accept referrals from NBT.Providing prehabilitation is a recommendation in the NICE guidelines for Brain Tumours and Brain Metastases (2018) as it has been proven to improve patient outcomes. Evidence from Manchester indicates it reduces hospital stay by 1.5 days. Ideally, prehab would be provided throughout the patient pathway, but initially this will be focused at the surgical centre due to limited resources. It is hoped that this will allow rehabilitation requirements to be anticipated and result in early onward referral to community services.The initial funding is for low grade and high grade gliomas only; it is hoped that the evidence gathered will prove that this is meeting an unmet need that will be beneficial to roll out to other brain tumour types such as meningiomas. **Action: An update on the progress of the pilot will be provided at a future CAG meeting.****5.3 Charity Involvement Updates*****Brainstrust***Regional Support Specialist (of which there are 6) R Hurley covers charity activities in Wales, Liverpool and Bristol. The charity is consistently reaching over 100 new patients and/or carers per month. The core work is provision of the coaching service which involves one to one sessions for patients to talk through any issues that they may have and try to find solutions. Rapid referrals can be made to the Braintrust team of counsellors. The charity is working to develop a clinical engagement programme, to build relationships with healthcare professionals and clinicians to see how the charity can help provide more tailored support. Further information is available on the website:<https://brainstrust.org.uk> Brainstrust are involved in research through their Patient Research Involvement Movement (PRIME). ***Brain Tumour Support***Trust and Grants Fundraiser D Courage represents Brain Tumour Support on behalf of T Skinner. The charity is back to full capacity within the region with two part-time staff each working three days a week and are currently providing support to over 177 patients, families and carers. In total there are eight support staff working for the charity, offering a dedicated counselling support service and a helpline.A new support worker has joined the team for the Oxford region, working alongside the John Radcliffe Hospital, which has resulted in a further 73 new referrals. Recruitment of a support worker for Wales is also underway.2023 will be the charity’s 20th anniversary year and will be running numerous awareness campaigns to promote activities. Further information is available via their website: <https://www.braintumoursupport.co.uk/> .Brain Tumour Support were thanked for their help with the Tessa Jowell Foundation nomination.**6. Clinical Opinion on Network Issues****6.1 Updates from Each Centre*****RUH:***Consultant Clinical Oncologist M Beresford continues to provide cover for neuro-oncology patients, with the majority of cases now managed by Consultant Clinical Oncologist K Falconer, who joined the team in February 2022 and Clinical Nurse Specialist (CNS) T Langdon. Thirty new referrals have been received from January to September 2022 in comparison to 23 new referrals during 2021. There are currently 52 patients on surveillance, 11 patients on treatment; in that group there are 21 GBM cases, for which the average survival rate is 16 months. ***NBT:***The most recent data from 2022 is new diagnoses of 200 primary brain tumour cases and an additional 100 meningiomas and metastatic cases. BNOG took part in a national survey looking at surgical activity during the COVID-19 pandemic and was found to be the only UK centre that did not cancel a single patient throughout the pandemic. This has been published in BMJ Open.The team comprises four Consultant Neurosurgeons. An additional Neuro-Oncology CNS, J Ryan, has now joined the team, which will enable equitable access of support to all metastatic patients by the whole CNS team, with help from the administrative support worker. The team is managing 425 patients in total at present. So far between September 2021-22, the team have seen 55 metastatic patients, 201 glioma patients, 113 of which were diagnosed with high grade tumours and 40 of which were diagnosed with low grade. 21 patients opted for surveillance and there were 27 palliative patients. 114 patients are currently on surveillance. ***BHOC:***Numbers remain stable at approximately 100 patients per year and approximately 70 skull base patients. There are now 5 neuro-oncologists who split the workload into management of adult gliomas, paediatric and skull base. An additional approx. 230 patients are seen per year for treatment of brain metastases with Gamma Knife, about 75% of which are brain metastases and 25% meningiomas or acoustic neuromas. There are two CNSs looking after the glioma patients, and an additional CNS is about to be appointed to look after all low-grade tumour patients from Grade 2 and below. This will help with this unmet need as, currently, these patients don’t have a point of contact and often have multiple long-term complex comorbidities. ***GRH:***The Cheltenham centre covers a wide geography with a population of approximately 1 million. The team comprises 1.6 WTE Neuro-Oncology CNSs and more recently 1.6 WTE neuro therapist and a support worker for all low and high-grade tumours. There is also access to two psychologists and epileptic nurse specialists on an ad hoc basis, and there are two dedicated Consultant Clinical Oncologists.Over the last 12 months there have been 93 new referrals (referrals are received from both NBT and Birmingham) in comparison with 70 patients in the year prior to the pandemic. Cases included 63 glioblastomas: 8 Grade 3 and 10 Grade 2.Gathering patient experience data is a priority and the team is keen to participate in the regional approach to this. GRH are recruiting to PARADIGM for palliative glioblastoma which involves radiotherapy in combination with Olaparib PARP inhibitor for palliative patients; this has reopened following the research pause during the pandemic and it is hoped that relevant patients can soon be identified; assistance from CAG would be appreciated.GRH are keen to reengage with the NBT MDT, which has been complicated due to job planning; S Gugliani will liaise with N Bora outside the meeting.**Action: To discuss GRH reengagement with NBT MDT meeting****6.2 28-day pathway mapping project****Please see the presentation uploaded on to the SWAG website****Presented by A Randle**Clinical Lead for Community Settings and Care for the SWAG Cancer Alliance A Randle, is undertaking a 28 Day Pathway Mapping Project, prompted by the national strategy to improve early diagnosis. It will investigate how the pathway can be improved from raising patient awareness of symptoms through to GP referral or alternative referral routes, including self-referral where appropriate, so that access to Primary Care does not become a barrier to early diagnosis of cancer.The 28 Day standard is a relatively new Cancer Waiting Time target to inform a patient of a cancer diagnosis or not within 28 days from GP suspected cancer referral. It will eventually replace the two week wait referral, but currently both are being reported.Very few referrals are received from GPs via the two week wait system; the majority present with a seizure or stroke to the Accident and Emergency Department. There are often sobering stories where patients report going to their GP for some time with symptoms that have not been recognised, which are difficult stories to unpick as initial signs of a brain tumour, such as headaches, can be subtle and frequently something else. Consensus from the group is to improve GP access to MRI imaging for patients with progressive subacute loss of central neurological function; access is not available with equity across the region and it would be cost effective to diagnose more patients at an earlier stage in comparison with the cost of a scan. The possibility of a central neuroradiology reporting system would also be useful to try and optimise reporting times. Support to implement a straight to test MRI process via the ICE system, with reporting within two weeks would be welcomed. This pathway has already been developed by the team and can be shared.If no abnormality is detected, the patient would be returned for appropriate management in Primary Care with input from neurology when required.**Action: A Randle to communicate the requirements for improved GP access to MRI with the Integrated Care Board and investigate how many GP practices within SWAG have access to MRI.** **6.3 Neuro-Onc MDT Mode Baseline Assessment****Presentation available on request from MDT members****Presented by H Dunderdale**Following publication of the Cancer Research UK report on MDT Effectiveness, which was then reproduced by NHS E, there is National support for implementing MDT reforms, and work is underway in many MDTs across the region to optimise the meeting environments. A baseline assessment of the Neuro-Onc MDT was undertaken in 2020 using the validated metric for the observation of decision-making audit tool MDT-Mode, developed by Behavioural Scientist Tayana Soukup and Consultant Urologist Ben Lamb during their PhD on improving MDT meetings. Resources relating to their PhD can be found on the SWAG website [here](https://www.swagcanceralliance.nhs.uk/cag-cancer-alliance-clinical-advisory-groups/ssg-documents/).It has been found that the audit cycle may need to be completed several times over the course of 2-3 years until an MDT meeting is considered completely optimised. The feedback is non-punitive with the data generated belonging to and presented back to the MDT professions to decide on any actions for improvements. Three meetings were observed on 16th September 2020, 23rd September 2020 and 30th September 2020. A total of 131 patients were discussed with 42, 48 and 41 discussed respectively within each meeting. The average discussion time per patient was 2.34 minutes, with the shortest discussion taking 60 seconds and the maximum discussion length 7.3 minutes. A total of 23 patients were deferred for discussion at a future meeting. It was noted that there are often complex cases discussed that take over 20 minutes.Now that multiple different MDT meetings have been assessed, there is a body of evidence to show that increasing the length of the average discussion time increases the quality of decision making. When looking at the MDT outcomes, a common theme for patients being deferred to a future meeting was missing information on the patient’s prognosis relating to their primary cancer. There were a number of discussions of cases that were for best supportive care; it was asked if these patients or any others could be discussed outside the meeting and listed for information if there was sufficient job planned preparation time to arrange this.Some MDTs that have preparation time have protocols that enable decision making to be made outside the MDT, with the patient still listed should anyone still want to discuss them. This has been seen to work successfully for a busy Urology MDT, with the MDT Coordinator and Surgeon having a pre-meeting and the pathologist and radiologist checking the outcomes and only discussing if there are any queries with the decision.Due to the complex nature of Brain and CNS Cancer cases, protocolised care may not be appropriate, but having preparation time to plan some decisions prior to the meeting may be helpful. The Radiologists have Tuesday to prepare.Types of information covered showed that History and Radiology scored high, with just a few incidences where the information was pending. Information on histology was scored slightly lower due to the number of deferred cases, which most likely reflects the workload pressures on pathology at present.Information on comorbidities was available for 60% of relevant cases, which compares well with other MDTs but could be useful to improve.The percentage of patient centred information was low; this was similar to other MDTs.Some MDTs have added a box to their MDT proforma to record patient views.Contributions scored highly for Surgeon, Oncology, Pathology and Radiology input. CNS input was scored at 46%. In MDTs where CNS contributions score higher, the percentage of patient centred information also improves.It has been frequently observed in the MDT meetings assessed to date that it can be challenging for the CNS to present their knowledge of the patient being discussed.The majority of patients referred to the MDT have not been seen beforehand, and so the team are reliant on the information provided by the referrer.It was felt that increasing the time per case discussion would allow the team to have more time to debate the decisions made and make a more nuanced plan. Another common theme across MDTs is the need to improve information output, which is somewhat hampered by the Somerset Cancer Register.Examples of practice to share with other MDTs were identified:* Case discussions are ordered to allow the neuropathologist to attend for an allocated slot
* The MDT member who knows the patient introduces the case history
* The meeting room is configured in a U-shape with three large screens which allow participants to see and hear each other clearly
* The MDT outcome is relayed directly to the MDT Coordinator, typed immediately into the Somerset Cancer Register, and checked for accuracy by the relevant attendees.

The report will be sent to the team to consider if it would be beneficial to implement any adjustments. Once these are embedded, the meeting can be reassessed to complete the audit cycle and see if any further adjustments are required. As the MDT meeting is long with no break, CAG are ask to consider the published proof that prolonged length of meetings can reduce the quality of decision-making after the first hour or 20 patients. The addition of a 10 minute break at this point has been shown to balance the quality of decision making and reduce the length of the overall meeting.Some MDTs have added the Rockwood Frailty Score to MDT Referral Proformas, which is commonly used in UHBW and by GPs.It would be ideal if there was additional time for discussion of Clinical Trials.The Somerset Cancer Register, which is often slow and not ideally configured, needs to be updated. User Representative A Holness recommends improving the information available on the patient’s view and enabling CNS contributions for this to be achieved. The only way to achieve this for new patients that haven’t been seen is to add a section for the information to the MDT referral form. Patients will always be involved in decision making when relaying the MDT outcome and will require input from the neuro-oncology team to discuss risks/benefits of treatment before making a decision. **Action: To incorporate a salient patient views and wishes / what has this patient been told / social situation box on the BNOG MDT referral form****Action: Consider incorporating Rockwood Frailty Score on referral form****Action: Incorporate a short break in the MDT meeting****Action: H Dunderdale to circulate findings to the Brain and CNS CAG members. Second audit cycle to review improvements.****7. Any Other Business**The sound quality for those attending the MDT via MS Teams is very poor. L Wilks will speak to A Rossiter, NBT Cancer Manager, to see if it can be improved.**Date of next meeting: Wednesday 17th May 2023, Engineers’ House / MS Teams****-END-** | **ACTIONS****AGREED****H Dunderdale****PhD Students/N Barua****V Iyer/K Kurian****L Wilks****L Wilks / Patient/User Representatives****C Moran/E Guiney****S Gugliani, N Barua****A Randle****V Iyer****MDT members****MDT members****H Dunderdale** |