



BRISTOL INTERSTITIAL LUNG DISEASE (BILD)SERVICE

Bristol NHS Foundation Trust

The Role of the ILD Clinical Nurse Specialist: An Evolving Journey



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Specialist Nursing Team · 2.74 WTE



Four Pillars of Nursing

01



Clinical Practice

Autonomous assessment, diagnosis, support and hands-on specialist care.

02



Leadership & Management

Coordinating the MDT and shaping the ILD service pathway.

03



Education

Educating patients, families and colleagues about the disease.

04



Research

Informing patients of trials and advancing evidence-based care.



NICE Quality Statements



People are diagnosed with idiopathic pulmonary fibrosis only with the consensus of a multidisciplinary team with expertise in ILD.



People with idiopathic pulmonary fibrosis have an ILD specialist nurse available to them.



People have an assessment for home and ambulatory oxygen therapy at each follow-up and before leaving hospital after an exacerbation.

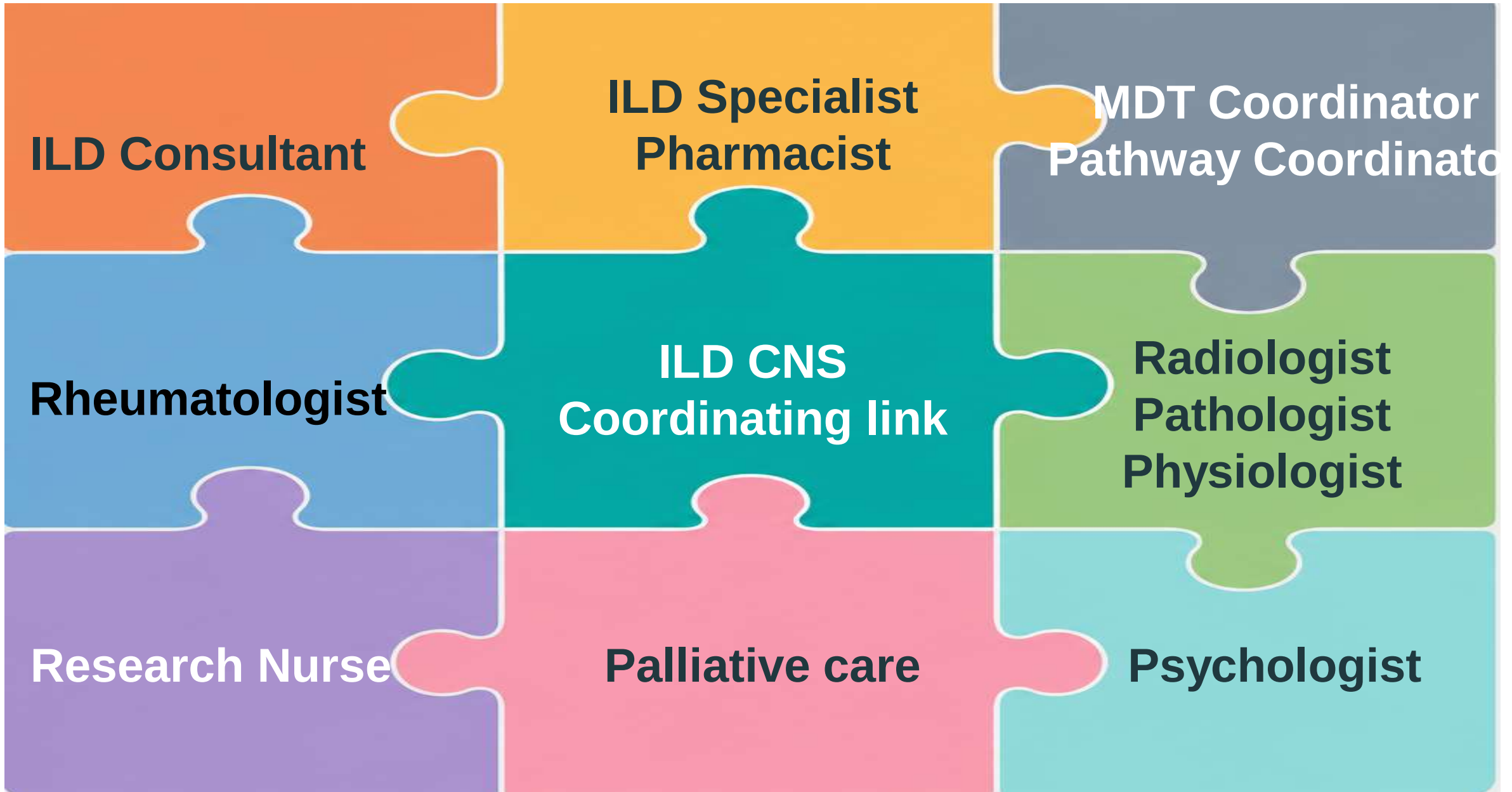


Pulmonary rehabilitation programmes provide services designed specifically for idiopathic pulmonary fibrosis.



People, their families and carers have access to services that meet their palliative care needs.

The ILD CNS connects the MDT



FROM REFERRAL TO ONGOING SUPPORT



The ILD Integrated Care Pathway

Adapted from the BILD integrated care pathway (2019)



Education

Condition-specific written
information & education



Assessment

Clinical needs
assessment



Treatment

Treatment options
discussed and agreed



Supportive care

Wrap around care

WRAP-AROUND SUPPORTIVE CARE

Oxygen

Pulmonary
rehab

Palliative
care

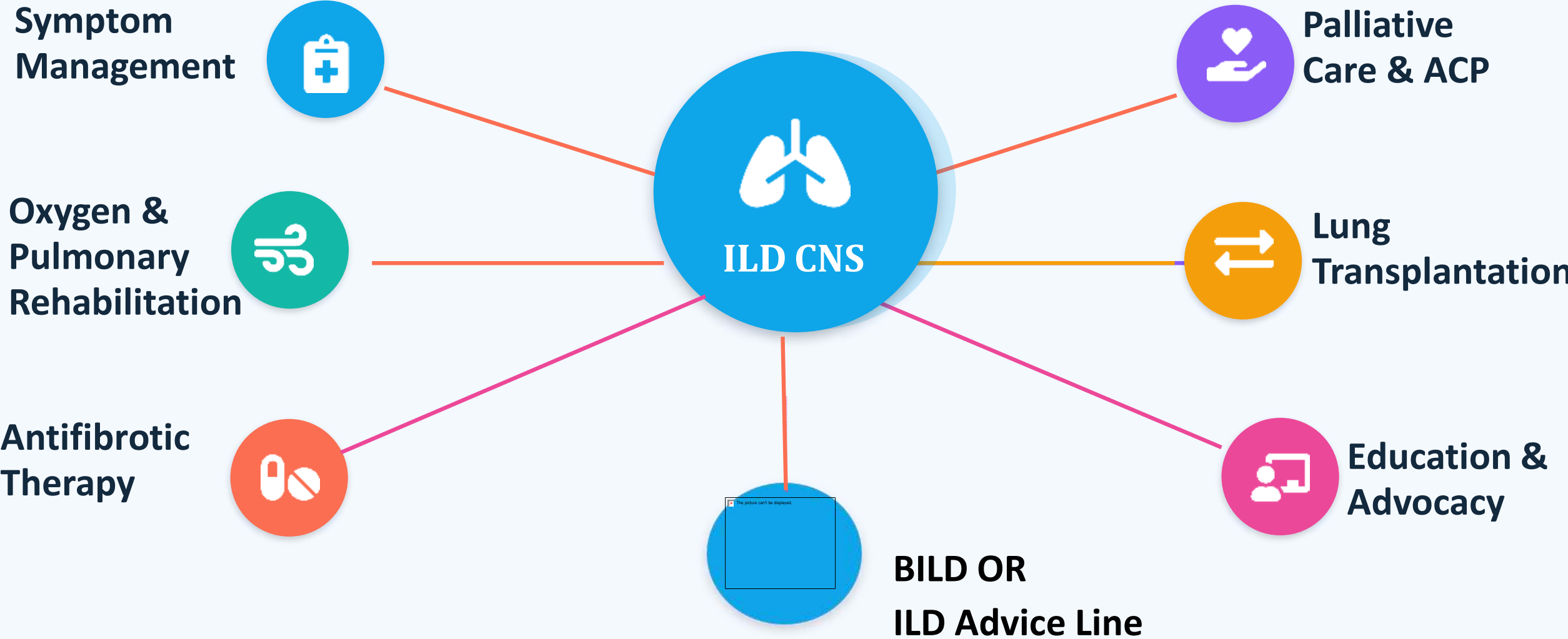
Psychology

Support
group

Transplant
referral



The ILD CNS at the Centre of Care





The Patient Journey Through the ILD Service



JOHN

61-year-old
previously fit & well

PRESENTATION

Worsening breathlessness after COVID-19
— previously swam 2 miles every morning

PMHX

Type 2 diabetes · Hypertension

MEDICATIONS

Amlodipine · Lisinopril

REFERRAL

GP → Respiratory HOT clinic; Bronchoscopy
+ BAL

Investigations



Lung function

FVC 2.33L (52.9% predicted) ,FEV1 2.10
L(61.9%predicted)) , TLCO not achievable



6-minute walk

SpO₂ 95 → 82% on air · 320 m covered (63% predicted)



Oxygen

Ambulatory O₂ 4–6 L initiated in the HOT clinic



Imaging & MDT

CT scan warranted an ILD MDT review

MDT DIAGNOSIS Idiopathic Pulmonary Fibrosis



Symptom Management & Disease Education



Clinician



Educator



Advocate



Coordinator



Support



“

Holistic, individualised and responsive symptom management — using autonomous clinical judgement to assess, initiate, review and adapt strategies in partnership with the patient.

Promoting patient autonomy and helping families retain control and quality of life despite the uncertainty of ILD.



Oxygen: Independence & Quality of Life

Patient goals



Remain active



Continue travelling



Maintain independence

AMBOX STUDY

- ✓ Improved breathlessness
- ✓ Improved health-related quality of life



IS THE BENEFIT STILL WORTH THE SIDE EFFECTS?



Antifibrotics: Beyond the Prescription



BENEFIT

Preserve lung function
Slow disease progression
Achieve personal goals



BURDEN

Diarrhoea
Weight loss
Impact on quality of life

Balancing benefits and treatment burden



Support



Monitoring



Shared
decision-making



Nutritional
support



Managing
side effects



Palliative Care: Living Well with ILD



**Emotional
support**



**Advanced care
planning**



**Palliative care
services**



**Breathlessness
management**

Palliative care is about improving quality of life alongside active treatment, not instead of it.



ACP Starts Earlier Than We Think



Diagnosis

Provide information

- Early, open conversations
- Understand disease & trajectory
- Begin end-of-life planning



Ongoing

Manage uncertainty

- Review prognosis, goals & hopes
- Discuss options and choices
- Manage evolving symptoms



End of life

Address emotions

- Alleviate fears
- Support decision-making
- Plans, affairs & preferences

WHO

Patient · family · health professionals

WHERE

Clinics · home · acute care · rehab

HOW

Discussion · shared decisions · documentation



The CNS in Lung Transplantation



From referral to transplantation — the ILD Specialist Nurse provides continuity

Support group: The Value of Peer Support



Do you have Pulmonary Fibrosis?

Are you supporting someone with Pulmonary Fibrosis?

COME ALONG TO A SUPPORT GROUP MEETING TO MEET OTHERS WITH SIMILAR CONDITIONS AND GET MORE INFORMATION / GUIDANCE.

ALL ARE WELCOME!

MEETING DATES
04/03/2026
03/06/2026
02/09/2026
02/12/2026
AT
COSSHAM HOSPITAL SEMINAR ROOM
LODGE ROAD, KINGSWOOD, BRISTOL
BS15 1LF
TIME: 1.30-3.30 PM

FOR MORE INFORMATION CONTACT:
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pulmonaryfibrosis.supportgroup@nbt.nhs.uk

TO REGISTER, PLEASE SCAN QR CODE



YOU CAN HELP THE PULMONARY FIBROSIS SUPPORT GROUP BY DONATING TO
THE REGISTERED NUMBER 2068
YOU CAN HELP THE BRISTOL ILD RESEARCH BY DONATING TO 8054



"Meeting John changed our perspective. His courage inspired my husband to keep using our motorhome and make the most of every day"

Shared experience

Practical advice

Hope and
Encouragement

Supporting Beyond the Patient



ILD Remembrance Service

A Time of Remembrance for the Families and Friends of loved ones cared
for by
The Bristol Interstitial Lung Disease Team

 **Service Innovation
Award-Winning PIP MDT**

 **Education & Leadership
BREATHES Study Day**



BILD CHARITIES



One Nurse Team, Continuous Care



Diagnosis

Assessment, education and coordination through the MDT



Living well

Oxygen, antifibrotics, PR, Support Group and symptom management



Advanced disease

Palliative care, ACP and transplantation support



*Living well, every day: mobility,
routine and independence.*

Individualised care · patient autonomy · quality of life despite uncertainty



REFERENCES

National Institute for Health and Care Excellence (2015). *Idiopathic Pulmonary Fibrosis in Adults: NICE Quality Standard (QS79)*.

Royal College of Nursing. *Four Pillars of Nursing: Levels of Nursing*.

Cambridge University Hospitals NHS Foundation Trust (accessed 02 June 2025). *The Breathing, Thinking, Functioning Model*.

Qinxue S, et al. (2026). *Heart & Lung*.

NHS England (2022). *Universal Principles for Advance Care Planning*.

Kalluri et al. (2022). *American Journal of Hospice and Palliative Medicine*.

Visca et al. (2018). *AmbOx Study. Lancet Respiratory Medicine*. [\[pubmed.ncbi.nlm.nih.gov\]](#)

Johnson et al. (2025). *MABEL Study. Lancet Respiratory Medicine*. [\[thelancet.com\]](#), [\[dyspneasociety.org\]](#)

Holland et al. (2026). *PFOX Study. Lancet Respiratory Medicine*. [\[thelancet.com\]](#), [\[pubmed.ncbi.nlm.nih.gov\]](#)

Bristol Interstitial Lung Disease (BILD) Service :Interstitial Lung Disease integrated Care Pathway



Questions?

Thank You.



**BRISTOL INTERSTITIAL LUNG DISEASE
(BILD) SERVICE**